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PARENT AND PROFESSIONAL PERSPECTIVES ABOUT AUTISM SPECTRUM
DISORDERS IN SOUTH INDIA: BELIEFS, PRACTICES, AND PARENT-PROFESSIONAL
RELATIONSHIPS

A dissertation submitted in partial fulfillment of the requirements for the degree of Doctor of
Philosophy at Virginia Commonwealth University

By:

NEERAJA RAVINDRAN
Master of Arts
SNDT Women's University, Mumbai, 2002
Master of Science
Virginia Commonwealth University, 2008

Major Director: Barbara J. Myers, Ph.D.
Associate Professor of Psychology
Department of Psychology

Virginia Commonwealth University
Richmond, Virginia
April 2012

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Abstract

PARENT AND PROFESSIONAL PERSPECTIVES ABOUT AUTISM SPECTRUM
DISORDERS IN SOUTH INDIA: BELIEFS, PRACTICES, AND PARENT-PROFESSIONAL
RELATIONSHIPS

By: Neeraja Ravindran, M.A., M.S.

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Major Director: Barbara J. Myers, Ph.D.
Associate Professor
Department of Psychology

The purpose of this qualitative study was to examine the experience of parents and professionals living in a large metropolitan city in South India who were raising and/or working with a child with an autism spectrum disorder. The study explored the unique perspectives of parents and professionals regarding their beliefs and practices about autism, as well as the nature of the parent-professional relationship. Nineteen parents (all mothers) and 21 professionals were interviewed in person at four schools, an early intervention program, a hospital clinic, and a physician's office. Themes were developed using qualitative software, and reliability was established through multiple coders and member checks.

The meaning of health, illness, and disability vary greatly across cultures and across time. Bronfenbrenner's ecological model provided the conceptual paradigm to examine how broad

cultural beliefs in the macrosystem, local services in the exosystem, parent- professional relationships in the mesosystem, and practices at home and school in the child's microsystem worked together to explain autism spectrum disorders for this group of participants at this point in history.

Four major themes emerged from the study that related to parents' and professionals' beliefs about causes of autism, expectations from treatments and services, nature of parent-professional partnerships in managing a child's autism, and the current 'state of things' with regard to autism in one South Indian city. Across the themes, parents and professionals embraced two seemingly contradictory yet perfectly compatible cultural beliefs: a modern, scientific approach and a traditional Indian viewpoint. The treatments offered to children were similar to Western practices, with the addition of traditional Indian practices (e.g., yoga, Ayurvedic medicine, Siddha). Parents were mostly happy and comfortable with their interactions with the professionals. Parents valued collaboration and respect but also acknowledged that the relationship was vertical in nature, with professionals having more authority. Professionals' assessment of their relationship with parents was influenced by their overall views about the families—positive or negative—which in turn was influenced by what they believed caused the child's autism (e.g., genetics/scientific causes vs. cold parenting and departure from traditional family structure). Services for children with autism in India are rapidly expanding, though the vast majority of those affected are not diagnosed or treated.

Parent and Professional Perspectives about Autism Spectrum Disorders in South India: Beliefs, Practices, and Parent-Professional Relationships

Autism Spectrum Disorder (ASD) is a complex developmental disability that appears early in childhood with severe and long-lasting effects for affected individuals and their families. It is now considered to be the most common developmental disorder (Bernier, Mao, & Yen, 2010) with a prevalence rate in the United States estimated as 1 in 88 children (Center for Disease Control, March 2012). Existing evidence from recent diagnosis and intervention research suggests that autism is neuro-behavioral in nature and co-occurs with intellectual disability in about 75% of those with the disorder (American Psychiatric Association, 2000; Dyches, Wilder, Sudweeks, Obiakor, & Algozzine, 2004). The causes of autism are not yet fully understood. Much evidence points to a genetic basis (Volkmar, Westphal, Gupta, & Wiesner, 2008), as epidemiological findings reveal that ASD is the most strongly genetic of psychiatric disorders, with a heritability factor greater than 90% (Bailey, LeCouteur, Gottesman, & Bolton, et al., 1995). Much energy also goes into researching potential environmental causal factors, including immunizations, heavy metals, infectious agents, or pharmacological agents (Volkmar et al., 2008). There is increasing evidence in the early intervention literature to suggest that early detection of autism that leads to early intervention is pivotal to improving developmental outcomes (Goin & Myers, 2004; Koegel, Koegel, Fredeen, & Gengoux, 2008). Intervention at an early age is considered more effective in treating various developmental disabilities because infancy and early childhood are critical periods of brain development, and during younger ages the brain has more “plasticity” to recover from injury than in later years (Odom, Hanson, Blackman, & Kaul, 2003). There is general consensus in the literature to suggest that for children

on the autism spectrum, participation in specialized intervention programs at young ages is important for optimizing long-term outcomes (Goin & Myers, 2004; Rogers, 1998; Volkmar, Paul, Klin, & Cohen, 2005). However, there is no consensus on what treatments might help what children. While some children on the autism spectrum who are treated early exhibit significant improvements in cognitive, social, and language functioning relative to older children with autism undergoing the same interventions (Rogers, 1998), there are other children who do not respond to the treatments that are so far available, regardless of the age at which they are offered.

Although shown to influence the course of ASDs in an important manner, the effect of cultural influences on diagnosis and treatment of ASDs has thus far received little attention (Bernier et al., 2010; Daley, 2002; Mandell & Novak, 2005; Ravindran & Myers, 2011). Bernier et al. (2010) observe that one of the reasons for this could be that neurodevelopmental changes appear to be much more significant in contributing to the impairments in social interaction, communication, and behaviors observed in children with autism, and the process of diagnosis and treatment planning in itself is lengthy and complicated. The process of early diagnosis and consequently early intervention procedures for children with autism across the world is a difficult goal to achieve (Ravindran & Myers, 2011). These difficulties stem from the layered challenges in establishing a consensus about what causes autism, implementing and measuring treatment outcomes, and making comparisons across cultures.

Given the dearth in existing literature on cultural perspectives, the current study examined the perspectives of parents and professionals in a large metropolitan city in South India about autism spectrum disorders. Specifically, the study aimed to understand autism spectrum disorders in the context of the Indian culture by examining parents' and professionals' beliefs about causes of autism, treatments and services used, and the nature of parent-professional

relationships in managing a child's disability. In addition, the study aimed to understand recent trends with regard to the community's attitude toward children on the autism spectrum and their families, and its impact on the availability of and accessibility to resources in the community.

If we consider all development to occur within a sociocultural framework, the single most important influence on the likely developmental pathway of a young child is the "sociocultural place on earth where the child is going to grow up," where *place* not only refers to the geographic locale, but also the "local community and its resources and ways of life, and its shared beliefs about development and disability" (Skinner & Weisner, 2007, p. 302). Within the sociocultural framework, Bronfenbrenner's Ecological Model of Development (Bronfenbrenner, 1994) provides a particularly useful theoretical framework to consider development and disability within the context of the overall ecology and to understand the interplay between various ecological systems that influence and shape development and management of disability.

For example, an important component of managing a childhood disability such as autism is the relationship between parents and the professionals delivering intervention services to their children (*mesosystem*, Bronfenbrenner, 1994). The ways in which professionals support children with disabilities and their families has the potential to enhance or hamper child and family outcomes (Dempsey & Keen, 2008). Early intervention literature in the United States suggests that a partnership approach where parents and professionals work in collaboration with one another, taking into account the needs of the family and child, is a preferred method of service delivery, rather than approaches to intervention that are paternalistic and vertical in nature (Carpenter, 2000; Case, 2000; Dempsey & Keen, 2008, 2009; Kalyanpur & Harry, 1997; Singh, 1995). Many researchers consider family-focused models of early intervention to be more humane and dignified for children with disabilities and their families (Carpenter, 2000; Dempsey

& Keen, 2008). Pivotal to the family-centered approach is its focus upon the needs of the entire family rather than just the needs of the child with a disability. Thus, the integral focus of this approach is on the nature of the partnership between the parents of the child with a disability and the professionals who work with the family. At its ideal, a partnership approach enables decision making and planning to be around mutually agreed upon goals, in which parents and professionals engage in a relationship that is defined by mutual trust, respect, and honesty (Dempsey & Keen, 2008).

Within an ecological framework, *macrosystem* factors encompass broad issues such as culture, governmental structures, the economy, and belief systems. The cultural norms of a child's ecology have an important role in shaping and influencing the nature of parent-professional relationships and their beliefs and practices about the child's disability (Bernier et al, 2010; Bronfenbrenner, 1994; Ravindran & Myers, 2011; Skinner & Weisner, 2007). Culture influences the way families perceive, cope, and seek help for their child's disability, as well as shapes and informs professionals' views of disability and their beliefs and practices.

Professionals may view the child's disability differently than parents because they view the disability from their own context (Singh, 1995). According to Singh (1995), notions of disability are contextual in nature and vary both between and within cultures. Culture is as much a process as an entity and is best viewed as an "ongoing process, system, or set of systems in flux" (Lopez & Guarnaccia, 2000, p. 574). It is essential to take into account the influence of cultural factors while trying to understand human disability because different cultures interpret disability differently. Disability can be interpreted as negative, positive, or a combination of both (Rogers-Adkinson et al., 2003). For example, there is no word in any of the languages of India for mental retardation or any of its derivative forms. In India, it is understood that every individual has a

place in this world and that all individuals must be accepted for who they are rather than what they are (Singh, 1995). Thus, although people in India may say that someone is of “weak intellect” (*mand budhi*—Hindi) or “lacks mental development” (*mAnsik avikAs rahit*—Hindi), they are usually not treated differently from those who do not exhibit these characteristics (Gabel, 2004; Singh, 1995). For a childhood disability such as autism, it is important to focus on both macrolevel cultural factors that are present in the dominant culture and affect people in the society and microlevel cultural factors that are present at the individual or family level that affect response to diagnosis and treatment choices (Bernier et al., 2010). For families and professionals, the meaning they attach to a child’s symptoms and their associated beliefs about the symptoms’ causes, prognosis, and most appropriate course of care are best understood within the context of culture (Mandell & Novak, 2005).

In the following literature review, information regarding culture and its impact on various facets of health and disability will be presented. It will begin with a discussion of the appropriateness of considering a sociocultural and ecological perspective of development when studying development and disability, followed by a description of Bronfenbrenner’s ecological model of development (1994) and a cultural framework for understanding psychopathology offered by Berry, Poortinga, Segall, and Dasen (2002). The review will then discuss cultural influences on the understanding and management of health, illness, and disability, with a special focus on autism spectrum disorders. Next, existing literature on parent-professional relationships in the area of health in general and childhood disabilities in particular, as well as family centered approach to care in the disability arena will be explored. Finally, the review will take a close look at childhood disability in the Indian context, with a special focus on autism spectrum disorders.

Review of Literature

A sociocultural perspective offers the opportunity to view a child's development and disability within the context of their local ecology and culture. According to Skinner & Weisner (2007), the sociocultural place where a child grows up has one of the largest influences on how the child's developmental trajectory is shaped and refined. While this is broadly true for development in general, the sociocultural perspective becomes especially important when we consider disability as a factor in a child's development. As observed by Skinner & Weisner (2007), sociocultural studies are those that "foreground the meanings, practices, constraints, and opportunities that individuals within disabilities and their families encounter and engage in throughout life, and how these evolve within broader social and political contexts" (p. 303). Thus, within a sociocultural perspective, in addition to their cognitive and/or physical manifestations, disabilities are viewed as sociocultural phenomena. Understanding and management of disability, including "how disability is defined and labeled, families respond and adapt, barriers and opportunities are created, differences in abilities are linked to other societal differences, and professional practices and institutions develop are all social and cultural constructions that have evolved over time at multiple levels within particular historical and political contexts" (Skinner & Weisner, 2007, p. 302). Thus, considering childhood disability within a sociocultural framework provides an especially useful perspective since it takes in to consideration all the factors that play a role in determining and shaping the child's possible life pathways, including the child's social context, ecology, resources, local meanings and understandings (Skinner & Weisner, 2007).

While there are many sociocultural approaches to studying child development and disability, Bronfenbrenner's Ecological Model (1994) paradigm uniquely supports the

understanding of individual development and disability within the context of environmental influences (Sontag, 1996). Although there has been limited research in exploring developmental disabilities within the ecological paradigm (Danescu, 1997), there is plenty of research that indicates the natural applicability of this paradigm to the field of developmental disabilities (see Skinner & Weisner, 2007; Sontag, 1996) and the usefulness of considering childhood disability within the Bronfenbrenner framework, especially in terms of special education and early intervention (Sontag, 1996).

Ecological Model of Development. All development, both typical and atypical, occurs within a sociocultural context and is influenced by transactional processes (Sameroff & Chandler, 1975; Skinner & Wesiner, 2007; Sontag, 1996). The ecological model of development proposed by Bronfenbrenner (1994) provides a theoretical structure in which to examine the interplay among various systems in the ecology that have an impact on development (Berry et al., 2002; Ravindran & Myers, 2011). Within this framework, human development is affected at multiple levels and by multiple processes. At the most proximal (close) level, human development is shaped and refined by immediate influences in the microsystem, and these influences have the most direct impact on development. These include the relationships a child has with people (e.g., parents, peers, teachers), the settings in which the child lives and grows (e.g., home, classroom, school), and the material elements available (e.g., food, bed, toys). The next, slightly more distal (distant) level is the mesosystem, which encompasses the inter-relationships between all the elements in the microsystem, such as the parents' relationship with one other, parent-professional relationships in a health care setting, and work-home problems in arranging schedules. The third and even more distal level is the exosystem, which involves the infrastructure of a city or region, including resources such as the availability of roads, utilities,

and police protections, as well as the capacity of the health and school systems to meet the specialized needs of a child with a disability. At the most distal (distant) level is the macrosystem, which brings us to culture, with all its beliefs, assumptions, and practices concerning health, government, spirituality, values, and the economy. Finally and arching over each of these levels, the chronosystem encompasses the notion of historic time, the reality that things change over the decades and the centuries (Bronfenbrenner, 1994).

The ecological system reveals itself as layers of influence, an interconnected system, in which the influences at one level flow naturally into the other levels. This makes it an especially useful model when examining culture and disability (Danesco, 1997; Ravindran & Myers, 2011). Proximal processes of home and family (microsystem), along with the inter-relationships between parents and professionals (mesosystem), work in conjunction with the more distal influences in the exosystem and macrosystem. And so we might find that, over time (chronosystem), if a culture becomes more accepting of children with disabilities, a nation might pass laws mandating enhanced disability policies for early intervention, schooling, and employment (macrosystem). At the exosystem level, cities would respond by requiring ramps and elevators in public buildings, and school systems would enact policies for individualized educational plans (IEPs). At the mesosystem level, tensions between husband and wife, as well as between parents and professionals might lessen as increased availability of resources helped them develop mutual respect and trust. Society in general (macrosystem) might become more accepting as citizens saw individuals with disabilities living productive lives. The child with a disability might then experience improved functioning, more independence, and a heightened quality of life. The trajectory of all these developments could go very differently in a society that

was closed and rejecting of children with disabilities and that, for instance, placed them in institutional settings, away from families and the public eye.

Cross-cultural Framework of Health and Disability. Given this sensitivity to a complex ecological model, the question remains of whether health problems and disabilities are the same regardless of where and when they occur. Is a broken leg a broken leg in any place in the world, at any point in history? Berry, Poortinga, Segall, & Dasen (2002) provide a cross-cultural framework that identifies three ways of defining health conditions: absolute, culturally relative, or universal. An *absolute* view of health and disability assumes that psychological phenomena are qualitatively the same across cultures. Thus, from the absolutist viewpoint, “schizophrenia” is “schizophrenia” no matter in what context or culture the symptoms occur. In the absolutist perspective, cultural influences play no role whatsoever in either the display or meaning of symptoms or characteristics. Assessments of such characteristics could be made using standardized diagnostic instruments, and interpretations would be made in an objective fashion, without taking culture into account. In this view, treatments, too, would work in a universal way. At the other extreme is *cultural relativism*, a position that assumes that all of human life depends upon the culture. In this view, diagnoses and interventions would be carried out using the values and meanings that a cultural group gives to a condition. The third perspective, *universalism*, lies between absolutism and relativism. Universalism both assumes that basic psychological processes are common to all members of a species and at the same time accepts that culture influences the development and display of these psychological characteristics. In this view, assessments and treatments would be based on the presumed underlying process, but measures and practices would be developed in culturally meaningful versions. There is no final answer to the question of sameness or difference of disability across

cultures. Rather, this framework draws our attention to the varying points of view on this important question (Berry, Poortinga, Segall, & Dasen, 2002).

Culture, Health, and Disability. We know who we are through the eyes of our culture. Our culture gives us our worldview, helps us make sense of what we know, and defines how we perceive everything that happens. Culture can be defined as a dynamic, yet stable, set of goals, beliefs, and attitudes shared by a group of people (Matsumoto, 2001). Although some beliefs held by members of a culture change over time, the general level of culture stays largely stable because the individuals change together (Gurung, 2006).

Culture and Health. What is good health, and what is illness? Both health and illness are in part cultural concepts, because our cultural background imparts and shapes how we perceive, experience, and manage health and illness (Mandell & Novak, 2005; Narayan, 2002). A mother makes decisions for her child on important health behaviors such as when and where to seek help when the child seems unwell to her, what kinds of treatments to use, how long to remain in care, and whether the child is better; each of these decision points is influenced by culture and could be made differently by an equally caring mother from another culture (Furnham, Akande, & Baguma, 1999; Gupta & Singhal, 2004; Narayan, 2002). Klienman (1986), in his description of healthcare systems as cultural systems, defines three social spheres within which “sickness is experienced and reacted to,” namely, the professional sector, the folk sector, and the popular sector. According to Klienman (1986), most decisions relating to health are made in the popular sector, including evaluations of when it is necessary to seek interventions within the other two social spheres, what type of interventions are appropriate, and decisions regarding compliance with treatment and perceived effectiveness. Thus, cultures develop their own health beliefs and health behaviors.

Health itself can be defined in many ways. Since its inception in 1948, the World Health Organization (WHO) has defined health broadly as a state of complete physical, mental, and social well-being (WHO; 1948, 2010). In contrast to this broad and positive view, health in Western medical circles is commonly seen as simply the absence of disease (Galanti, 2004). This biomedical view of health focuses on the biological aspect of life, and it defines health in terms of “non-health.” However, other societies conceptualize health in broader ways (Gurung, 2006). For example, Ayurveda, or “Knowledge of Life,” is an ancient yet still widely practiced Indian system of medicine that views health as a harmony between the body, sense organs, mind, and soul (Dash, Junius, & Dash, 1997). Similarly, Traditional Chinese Medicine views health as a balance between yin and yang, the two complementary forces of the universe (Kaptchuk, 2000), which are often translated into “hot” and “cold” qualities of an individual (Gurung, 2006). According to Alvord & Van Pelt (2000), in the Native American Navajo tribe, health has to do with achieving a balance between human beings and the spiritual world.

Culture and Disability. The concept of disability, too, varies across cultures and different times in history. Since cultural factors are intertwined with practical daily activities, they may assume a pivotal role in the way families interpret and address deviations in their child’s development (Mandell & Novak, 2005). Thus, although disability has happened throughout history and is prevalent in all cultures around the world, the meaning and implication of disability vary greatly both within and between cultures and across time (Skinner & Weisner, 2007). The International Classification of Functioning (ICF), WHO’s framework for measuring health and disability, puts disability in a normative framework. As noted by Ravindran & Myers (2011), the ICF sees disability as a mainstream and universal human experience, and asserts that every human being experiences some degree of disability as a result of natural decrements in

health that occur over the course of the lifespan. By shifting the focus from cause to consequence, the ICF “places all health conditions on an equal footing, allowing them to be compared using a common metric—the ruler of health and disability” (ICF, 2009, p.4).

Perhaps the most crucial aspect of this definition is that it does not see disability only as a medical or physical dysfunction but rather takes into account the social aspects of disability. By looking at the context of an individual in a family and a community, the ICF allows us to appreciate the impact of the cultural context on a person’s functioning (Ravindran & Myers, 2011). Hall and Hill (1996) observe that the extent to which a disability imposes a “handicap” for an individual is determined not only by the severity of the condition but also by family attitudes, financial resources, adaptations in the physical environment, legislation to support individuals with disability, and the prejudice (or acceptance) of society. For example, poor vision or even blindness is less of a handicap in a society that provides eyeglasses, adaptive devices like recorded books or computers that “speak,” public transportation, laws that promote equal opportunity in hiring, and family members who are accepting and positive. As observed by Gartner, Lipsky, and Turnbull (1991), “Responses to impairments are not ‘natural;’ rather they are invented, different at one time or another, from one culture to another” (p. 18). In other words, depending in part upon the context, a “disability” may or may not be a “handicap” in an individual’s life.

Cultural Variability in Interpretation of Disability. According to Groce and Zola (1993), chronic illness and disability are seen by some cultures as a form of punishment. For example, in the Puerto Rican culture, mothers may be blamed if they give birth to a child with a severe disability, and the child may be viewed as a penance for the mother’s sins (Rogers-Adkinson et al., 2003). This is similar to what is sometimes seen in the Indian culture, where the family and

society may believe that the child's disability comes about as a punishment for sins committed by the child or parent in a past life (Groce & Zola, 1993). In certain Mexican cultures, disability is seen as the result of a curse placed on a family by an enemy or someone giving them the "evil eye" (Rogers-Adkinson et al., 2003). Klienman et al. (1995) found that among Chinese participants, chronic illness was seen as taking away an individual's legitimacy.

On the other hand, some cultures interpret disability in a neutral or positive way. Rogers-Adkinson et al. (2003) observed that a variety of interpretations of disabilities exist across Native American cultures. For example, the Navajo tribe views a person with a disability as a teacher for the clan. They believe that such a person brings special lessons to the tribe and offers a "sixth sense" or a unique gift (Medina, Jones, & Miller, 1998). Thus, a family might be cautious in accepting specialized treatment for their child with a disability, as doing so could potentially interfere with the delivery of his or her message to the tribe. In addition, in Navajo culture, children with disabilities participate in all traditional aspects of child and family life, rather than being kept in a separate place (Rogers-Adkinson et al., 2003). Given that diverse cultures around the world adopt such varied and widespread approaches to health and illness, it becomes crucial to view health and disability in culturally sensitive ways and to develop culturally sensitive interventions. As suggested by Daley (2002), it is flawed to assume that treatment methods developed in the west can be blindly generalized to children with disabilities across the world. Such treatments might, or might not, work in the same way for children across different cultures. Whether the treatment is efficacious could depend in part on whether the family chose to implement it or, instead, to reject or ignore it.

Cultural Influence on Beliefs and Practices. Beliefs exist both at a cultural level in the macrosystem and more proximally, in the minds of individuals. At the microsystem level, family

members greatly influence a child's life through their beliefs regarding the cause of a disability, their ideas about the worth of a person with a disability, and their acceptance of a person with a disability (Danesco; 1997; Groce & Zola, 1993). It was not long ago that most families in the U.S. placed a child with a disability into an institutional setting, where the child would lead a segregated life; such facilities still exist. These families no doubt experienced heartbreak at leaving their child but also believed strongly that this was the best action to take, both for the child and for the entire family. Thus, families' beliefs affect the child's participation in social activities, the resources they spend on the child, and their expectations for what their child might achieve in adulthood. Families' beliefs about disability are not just peculiar to those parents but rather arise from the overarching beliefs and values of the society, including macrosystem elements that are economic, political, social, and spiritual (Danesco; 1997; Ravindran & Myers, 2011).

Parents' beliefs about what caused their child's disability play a role in what they do for their child (Danesco, 1997). For example, Mirza, Tareen, Davidson, & Rahman (2009) noted that families in Pakistan who believed that their child's intellectual disability was due to "Allah's will" were more likely to consider their child's condition as unchangeable and believe that they ought to only take care of their child in the most basic sense, for which Allah would reward them. As per one participant in their study describing his child, "We don't have to make him get better. We only have to feed him, wash his clothes and clean him overnight etc. This awareness is very important" (Mirza, et al., 2009, p 564). Trotter and Chavira (1997) report that Mexican Americans believe that there are both biological and spiritual causes for illness. While they believe that a medical doctor can cure the biological problems, only *curanderos* or healers can be trusted to cure spiritual problems (Gurung, 2006). On the other hand, a family that believes that

their child's condition is caused by specific biological variables may seek medical treatments to reverse that physical problem, while those who believe the cause came from some agent in the environment or from a specific experience may seek behaviorally-based interventions (Ravindran & Myers, 2011). For example, parents who believe that autism is caused by vaccines often seek to alter their children's physiology through chelation to remove what they believe to be heavy metals; those who accept a "leaky gut" theory may use a restricted diet or probiotics; while those who believe that sensory issues are at the core of their children's problem may use a non-biological CAM (complementary and alternative medical) treatment such as auditory integration training (Levy & Hyman, 2003).

Parents' beliefs about causes also inform what they expect their treatments can do (Danesco; 1997; Ravindran & Myers, 2011). For example, some parents of children with autism are convinced that if they find the right interventions and use them faithfully, their child will be "recovered" or cured of the condition (Christon, Mackintosh, & Myers, 2010; Mandell & Novak, 2005); these positions are often promoted through books and spokespersons in the popular press (e.g., McCarthy, 2008). By contrast, parents are more likely to accept their child's condition as fate or destiny and have lower expectations of cure or improvements from any treatments used if they embraced a fatalistic view of their child's disability (e.g., God's will). Others, from many faith traditions, may adopt spiritual practices in their own lives (e.g., prayer, fasting) with the faith that this will help their child to improve. Thus, the cultural and spiritual background of a family and the larger society plays an important role in the beliefs parents hold with regard to causes about their child's disability and expectations for their child's future (Ravindran & Myers, 2011).

Cultural Influence on Availability of Resources. At the exosystemic and macrosystemic levels, cultural factors influence the kinds of resources available to children with disabilities. For example, in most of the Western world, education is available to all children, regardless of disability. However, in cultures with very limited resources, education may be reserved for the most capable children or those who are seen as most able to help their families economically, especially when even the typically developing and healthy children might go without education (Ravindran & Myers, 2011). In some societies a child with a severe disability is not expected to survive, and so it seems reasonable in these cultures to allocate scarce resources of medical care and parental attention to their healthier children; according to Groce & Zola (1993), this cultural expectation can become a self-fulfilling prophecy if a sickly infant is not fed and tended. In 2009, a news note from UNICEF reported that, “Fewer than five percent of children with disabilities are attending school, and in some cases the figure is less than one percent.” As observed by Ravindran & Myers (2011), in the U.S., the federal government did not enact a requirement for public schooling for children with disabilities until 1975 (Education for All Handicapped Children Act, P.L 94-142). Even for nations that try very hard to educate all children, money and resources affect the education available to children with disabilities. Special education costs more to deliver than does education for typically developing children, as it requires specialized teacher training, supplies, and facilities. Cost and reimbursement issues present barriers to assessments and treatments (Shattuck & Grosse, 2007), and there is great variability across states and across disability groups (e.g., intellectual disability, physical disability, mental illness) in terms of how much public financial support is provided (Braddock, 2002). As noted by Braddock, an important underlying reason for the variability in state-to-state commitments for disability programs stems from the semi-autonomous role constitutionally

granted to state governments in the federal system of the U.S. This system is different than European nations, where there are nationally uniform policies for provision of health care, education, and social welfare. Thus, these exo- and macrosystem differences in the structure of national governments trickles down to the life of an individual child with a disability who may or may not have access to a classroom, social services, and health care (Ravindran & Myers, 2011).

Cultural Influence on Help-Seeking Behaviors. Cultural factors also influence who families go to for support. Families from collectivist cultures (e.g., India, Mexico, China) rely heavily on their family and friend support networks; they are less likely to seek help from medical or professionals service sectors, as these are not the people they know and trust (Dyches, et al., 2004; Ravindran & Myers, 2011). For example, Mexican-American parents sought support from their informal networks—church members, neighbors, and extended family—in addition to seeking professional help when their children were ill or disabled (Danesco, 1997). Similarly, they also practiced cultural prescriptions such as the use of home remedies, seeking the help of *curanderos* to remove the hex of a “brujera.” These parents embarked on prayer pilgrimages and fulfilled special vows to “cure” the child or minimize the severity of the symptoms (Danesco, 1997). Thus, parents in this culture relied largely on their social support network in their quest to understand, treat, and accept their child’s disability. In an online survey of Indian parents of children with autism spectrum disorders, Ravindran & Myers (in press) found that parents whose extended family offered support and acceptance had a more positive view of their child’s disability than did those who experienced criticism or rejection from the child’s grandparents. In contrast to these families who sought support from their own families and friends, in an online survey of nearly 500 families from Western cultures (e.g., United States, Canada, England), parents ranked “other parents of child with ASD” as a source of support (68%) more often than

they did their own family members (53%) (Mackintosh, Goin-Kochel, & Myers, 2006). These “other parents” were people they would never have met if their child did not have this diagnosis, and yet they were the most-endorsed source of support. These people who had “walked in my shoes” became close friends and confidantes to parents who were struggling to know what to do for their child with autism. So while there is a universal need for personal support (Sivberg, 2002; Weiss, 2002), parents of children with disabilities from different cultures seek this support in different ways.

Cultural Influence on Parent-Professional Relationships. Macro-level cultural factors “trickle down” to influence factors in the mesosystem such as relationship between parents and the professionals who provide interventions for their children (Ravindran & Myers, 2011). An important aspect of the parent-professional relationship, and one that is embedded in cultural and social norms, is professionals’ and families’ beliefs about the degree of authority each should hold. These views can range from a paternalistic view that “doctor knows best,” to the other extreme of the parents’ having an innate understanding of their child’s needs, to a collaborative sharing of authority between the professional and the family. The relationship between families and professionals is significant because in many cases getting a diagnosis, as well as gaining desired treatment, rests in part upon the quality of their communication (Goin-Kochel, Mackintosh, & Myers, 2006; Kaba & Sooriakumaran, 2007). Research indicates that parents in the U.S. often complain that professionals do not listen to them or take their views seriously (Ahern, 2000), and that parents sometimes respond by seeking another doctor or by searching for treatments on their own (Christon et al., 2010; Goin-Kochel et al., 2006). Though an interdisciplinary or transdisciplinary teamwork model is a goal embraced by many professionals in the U.S. (Berman, Miller, Rosen, & Bicchieri, 2000; Gettinger, Stoiber, Goetz, & Caspe,

1999; King, Strachan, Tucker, Duwyn, Desserud, & Shillington, 2009), this degree of collaboration and power-sharing is hard to achieve in practice, in part because of the high cost of interdisciplinary work (Pearson, 1983; Shattuck & Grosse, 2007). While most Western cultures at least aim to create a partnership-based approach between parents and professionals (Gallagher, Rhodes, & Darling, 2004; James & Chard, 2010; Whitehead, Jesien, & Ulanski, 1998), other cultures across the globe maintain a view of parents as “uninformed and in need of help” (Seligman & Darling, 1997, p. 95; Harry & Kalyanpur, 1994) and are not desirous of such a partnership.

Evolution of the ‘doctor-patient’ relationship. Kaba and Sooriakumaran (2007) outlined the evolution of the doctor-patient relationship in a medical setting from 4000 B.C. to present day. According to their review, in the past, patients were most often considered to be too ignorant to make their own decisions, and thus, professionals considered informing the patients about the uncertainties and limitations of medical interventions as undermining the patient’s faith in their ability to cure. During this period, doctors felt that it was their responsibility to make decisions on behalf of their patients. As the political, economical, and social distance between doctors and patients widened, the doctor-patient relationship became increasingly impersonal, remote, and based upon negotiations and financial transactions (Kaba & Sooriakumaran, 2007). In the present day, however, the doctor-patient relationship has evolved to create a new alliance that is based on cooperation, mutual respect, trust, and open communication (Dempsey & Keen, 2008; Kaba & Sooriakumaran, 2007). While the alliance-based relationship is seen prominently in Western cultures, the doctor-patient relationship in older civilizations such as India and China has remained more constant (Kaba & Sooriakumaran, 2007). There is evidence in the literature

that in these societies, a paternalistic approach still dominates, and doctors continue to maintain very high status in the society (Kaba & Sooriakumaran, 2007; Singh, 1995).

Kaba & Sooriakumaran (2007) identify two main reasons for the paternalistic trend to continue in East Indian societies. First, teachings of major Eastern religions (e.g., Hinduism, Buddhism) deem the art of healing as the most worthy work to aspire for, thus granting a higher status to individuals in the field of health and healing. Second, litigation rates of doctors in Eastern societies are lower compared to the escalating claims of medical negligence in the UK, Australia, and USA. In addition, factors such as rapid technological growth, including wider access to the internet, higher rates of literacy and education, and more stringent laws regarding patient rights in Western societies, may contribute to greater awareness, access, and empowerment in the health care process for families and patients in the Western world.

A similar vertical (i.e., professionally-dominated, hierarchical) relationship is seen in many Asian cultures between families of children with disabilities and the health care professionals who provide different services to their children (Harry & Kalyanpur, 1994). Parents in most non-Western cultures rarely see themselves in an equal relationship with professionals. These parents are limited in their ability to advocate for their child with a disability due to professional dominance in the parent-professional relationship (Case, 2000). In most cultures across the world, but particularly Asian cultures, professionals (e.g., doctors, therapists, educators) are viewed by most families as well-trained and qualified, with primary responsibility for their child's welfare (Case, 2000). Kalyanpur and Harry (1997) viewed the power differences between parents and professionals in these societies as so pronounced as to adversely affect the quality of the parent-professional relationships.

Family-Centered Approach to Intervention. Evidence from the early intervention literature indicates that a family-centered approach to intervention is increasing across the world (Carpenter & Phil, 1997; Carpenter, 2000; Dempsey & Keen, 2008, Kalyanpur & Harry, 1997). Parents of children with disabilities play various roles in their child's life, including that of advocate, information seeker, public educator, and spokesperson (Dunst & Dempsey, 2007). These roles become more complex as parents' level of involvement with a wide variety of community service providers increases. According to current American views, the expansion of parental roles increases desirable outcomes in various educational, therapeutic, and transitional settings for the child and the family (Dunst & Dempsey, 2007).

In the United States, family-centered approaches in early intervention were strengthened through macrolevel processes such as the introduction of new legislation in the 1970s and 1980s (Carpenter & Phil, 1997). A beginning point for such legislation was Public Law 94-142, the Education for All Handicapped Children Act, passed in 1975. This act was the first law to clearly define the rights of school-aged children with disabilities to a free and appropriate public education in the US, to be delivered in the "least restrictive environment." It required that the school include parents when meeting about the child and planning the child's Individualized Education Program (IEP). In 1986, P.L. 99-457 asked states to expand eligibility to younger children, age 3 to 5. States were also invited to develop a plan to serve infants and toddlers under a provision called Part H; all 50 states complied. Under Part H, the family's role became a major focus. An Individualized Family Service Plan (IFSP) was required for each child/family served. The passage of P.L.101-476 in 1990 renamed this set of services Individuals with Disabilities Education Act (IDEA), replacing the word "handicapped." Further amendments occurred in 1997 and 2004. In each of these new acts and amendments, there were shifts toward making the

focus of special education a family-oriented service, intended to enable and empower the families by involving them in the decision-making process for their child with a disability (Kalyanpur & Harry, 1997). The IFSP includes areas of emphasis that reflect the concerns, resources, and priorities that parents identify for themselves and their children (Carpenter & Phil, 1997).

According to Dunst & Dempsey (2007), effective relationships between parents and professionals have empowering benefits for parents, and consequently, desirable outcomes for their child. Emerging evidence in this area indicates that a partnership approach between parents and professionals is perceived by parents of children with disabilities as being most effective across different cultures. For example, in samples of children with disabilities from Australia and India, Dempsey, Foreman, Sharma, Khanna, & Arora (2001) found that family-professional relationships which were defined by mutual respect, trust, and equality—what they called “enabling relationships”—were a significant predictor of empowerment above and beyond other variables such as personal characteristics and socio-economic status of the participants. The term “empowerment” in the family-centered-care literature usually refers to the attitudes, knowledge, and behaviors associated with perceptions of control, competence, and confidence (Dempsey et al., 2001; Dempsey & Dunst, 2004). In two different studies, Dempsey and Dunst (2004) found that there was a positive association between enabling practices and empowerment among parents of children with disabilities in the United States and Australia, regardless of differences in the background characteristics of the participants. Research indicates that an over-reliance on professional input can disempower parents, causing feelings of inadequacy and encouraging the tendency to problem-solve only when supported by professionals (Carpenter & Phil, 1997). Needless to say, this can have an impairing effect on the parents’ or families’ coping and stress

related to their child's disability, which could then hamper the quality of intervention provided to or received by the children. At least for families in the Western world, family-focused models of intervention are considered more humane and dignifying for children and their families (Carpenter, 2000). Family-focused models acknowledge the context of the child, take into consideration the associated demands and limitations for the child and the family, and introduce appropriate, sustainable, and sensitive interventions (Carpenter, 2000).

Cultural Views about Autism. With regard to autism spectrum disorders, it is essential to attend to culture when considering beliefs about causes and treatments for autism, regardless of whether we approach it from a Western medicine perspective or from the perspective of other cultures (Ravindran & Myers, 2011). The Western view of autism in its earliest years took culturally relative views (Berry et al., 2002) that the field completely dismisses today. For example, autism was first seen as a disorder that occurred only in children of very intelligent parents and the upper class (Daley, 2002). Kanner introduced this idea in his seminal 1943 paper in which he observed, "There is one other very interesting common denominator in the backgrounds of these children. *They all come of highly intelligent families*" (p. 248, italics his). Although he made no direct causal attributions, Kanner also raised the question of whether autism develops due to coldness in the parents: "One other fact stands out prominently. In the whole group there are very few really warmhearted fathers and mothers" (p. 250). This theme was taken up and spread by Bettelheim (1967), who believed he saw a valid parallel between concentration camp survivors and children with autism. As noted in Ravindran & Myers (2011), Bettelheim believed that children with autism should be removed from their homes and treated with psychoanalytic therapy in a residential setting; he established these practices in a university school setting where he worked from 1944 to 1973. It is unclear whether Bettelheim was the first

to coin the term “refrigerator mother,” but this term became attributed to him in the popular media. Taking another culturally relativistic stance, in 1984, Sanua asserted that, “infantile autism is an illness of modern civilization” and thus limited geographically to countries with high technological advances, thereby ruling out the existence of the disorder in countries like India and China. These views are rejected today and are seen as both wrong and harmful to the parents who were hurt by such painful attributions of blame (Dyches, et al., 2004).

These relativistic positions stand in contrast to an absolutist position that views autism as a disorder that is invariant in its manifestation across cultures. A disorder that is invariant across cultures will most likely have an organic cause (Berry et al., 2002). Although the exact causes of autism are still unknown, there is evidence in current research for a biological basis (Volkmar et al., 2005). However, interpretation and range of expression of this biological condition are likely to vary widely according to culture. The middle position in Berry et al.’s classification scheme views autism as a universal disorder which, like schizophrenia, occurs in some form in all cultures, though still susceptible to cultural influences in expression and course (Daley, 2002). Whether or not the affected individuals differ in objective terms, it is likely that others in society would interpret and understand their characteristics in culturally disparate ways (Dyches, et al., 2004).

Culture Influence on Treatment Decisions about Autism. Cultural factors assume a major role in the way families subscribe to intervention strategies (Danesco, 1997; Mandell & Novak, 2005; Ravindran & Myers, 2011). There is an overwhelming array of treatments available for autism, including behavioral, cognitive, pharmaceutical, sensory, relational, vitamin, and diet therapies (Christon et al., 2010; Goin-Kochel, Mackintosh, & Myers, 2007). As there is no universally accepted treatment for autism, parents play a primary role in deciding

what treatments to seek for their child. Cultural beliefs about the cause of autism influence families' decisions. For example, in China, two distinct causal interpretations of autism exist (Hsiao & Magyar, 2006). Traditional Chinese Medicine (TCM) of the 18th century asserts that all mental illness, including autistic disorder, is related to vital and spiritual forces and to healthy life practices in the social, cultural, and political realm. According to Hsiao & Magyar (2006), based on beliefs in causes, Chinese parents' treatment choices vary from applied behavior analysis to acupuncture and herbal medicine. Parents in Taiwan attributed their child's autism to both biomedical and supernatural etiologies, without apparent conflict, and combined Western biomedical treatments with supernatural remedies (Shyu, Tsai, & Tsai, 2010). By contrast, the notion of autistic disorder based on the Western psychiatrist system indicates that the disorder is neurological in nature. Still, untested complementary and alternative medicine (CAM) approaches are tried by a majority of families in the United States, although limited evidence exists regarding the efficacy of such treatments (Christon et al., 2010; Levy & Hyman, 2003; 2008). Hyman and Levy (2005) observed that parents sometimes first try these treatments out of frustration when conventional treatments are ineffective or unsatisfactory; they sometimes keep the treatments to themselves, not telling the physician (Wong & Smith, 2006). However, as noted by Herbert, Sharp, & Gaudiano (2002), while some CAM therapies and traditional healing practices could be beneficial or neutral (i.e., cause no harm), other untested treatments could be harmful to the child. In an online-based study exploring beliefs and practices regarding autism in Indian families now living in the US or other countries, some Indian parents were using yoga, Ayurveda, and homeopathy with their children (Ravindran & Myers, in press). These treatments were used in combination with conventional treatments (e.g., speech therapy, ABA, social skills

training) and not as the sole intervention by parents who were largely Western in their careers and lifestyles but maintained a respect for their Indian heritage.

Cultural Influence on Parental Expectations for Child's Future. Beliefs about causes also inform parents' beliefs about the expected course of their child's autism, including expectations about whether it will be a lifelong disability or whether the child will show substantial improvement or even "recovery" (Danesco, 1997; Mandell & Novak, 2005; Ravindran & Myers, 2011). If a family believes that their child's autism is curable, they may follow an intervention plan that promises a high probability for recovery. Organizations such as *Autism Research Institute* suggest that recovery or near-recovery is likely if the appropriate biomedical treatments are used, and they ask parents to sign up on their website when their child appears recovered (Ravindran & Myers, 2011). Currently, however, there are no well-designed clinical studies to support such extreme claims (Herbert, Sharp, & Gaudiano, 2002; Levy & Hyman, 2005), and claims are often based on case studies and testimonials rather than objective research (Heflin & Simpson, 1998). By contrast, if families believe that autism is a life-long disability, whose symptoms and related disability may be alleviated to some degree but not eliminated completely, they are likely to use more established treatment choices and have more modest expectations from those treatments (Mandell & Novak, 2005).

Need for More Cultural Studies on Autism. Daley (2002) observed that there is a significant discrepancy between the research evidence supporting understanding of autism in a cultural framework and the actual number of cultural or comparative studies available. Few researchers have attempted a comparative approach or explicitly addressed cultural factors, and most of the current studies on autism spectrum disorders emanates from a Western cultural perspective (National Research Council, 2001). Despite the important role that culture may play

in influencing treatment choices families make, a dearth of research has examined this issue in children with autism (Mandell & Novak, 2005). Berry et al. (2002) observe that “cultural factors are likely to effect the definition and recognition of symptoms, if not also treatment and course.” According to Gilliam and Coleman (1982), beliefs about causes are likely to dramatically affect models of treatment in autism. Thus, beliefs of one culture should not be generalized to others without careful consideration and full awareness of the potential problems.

According to Daley (2002), the lack of sufficient cross-cultural research on autism may reflect that some researchers have assumed that autism is rare in non-Western countries (Egdell & Nikapota, 1991; Varma & Chakrabarti, 1995), an “illness of modern civilization” (Sanua, 1984). It might also reflect that others believe that there is little variation in the behavioral manifestations of autism (Campbell, 1996) and that there is no difference in any aspects of the disorder across different cultures, ethnicities, and social class (Cuccaro et al., 1996). Others argue that not only are the same behavior patterns seen, but also the “problems of the individuals and their families are virtually the same, and the required responses are quite similar” (Morgan, 1996). In effect, these findings seem to assume that the manifestations of autism—and of families’ response to autism—follow a universal pattern, and hence, it is unnecessary to take a cross-cultural view point.

However, while certain manifestations of the disorder may follow a universal path, expression of symptoms, meaning associated with the condition, beliefs about cause and effect, treatment options and availability, and quality of care are likely to vary vastly based on culture (Bernier et al., 2010; Daley, 2002; Mandell & Novak, 2005). Considering the important role of culture in almost every aspect of our everyday lives, it is necessary to rethink such an absolutist view of autism or any disability. Daley (2002) points out several reasons why it is necessary to

conduct cross-cultural studies in this area of research. If the assertion that there is little or no variation in the presentation of symptoms is correct, then studying autism within a cultural context will help us better understand culture. Also, explanatory models about autism vary from culture to culture, depending on beliefs about normative development and the relative value of different behaviors in a culture (Daley, 2002; Dyches et al., 2004; Mandell & Novak, 2005). In addition, there is variation in the meaning attributed to a particular symptom (Daley, 2002; Mandell & Novak, 2005). Finally, other areas such as the process of diagnosis, help-seeking behaviors in parents, treatment choices, family functioning, and community and legal issues (Daley, 2002; Mandell & Novak, 2005) are all factors in an individual's ecology that are deeply shaped and molded by their sociocultural context and have a significant effect on their everyday lives and the lives of their families.

Disability in the Indian Context. India is an extremely diverse nation. With more than 2000 ethnic groups, over 1600 languages, and all the world's major religions, it is impossible to generalize on what all Indians believe or practice. In India, child-rearing practices differ across regions, but there are certain common factors. The birth of a child in India is invariably seen as a "gift from God," and illness or disability is sometimes (but not always) considered the result of previous sins or of a stranger or neighbor giving the "evil eye" (Kaul, Mukherjee, Ghosh, Chattopadhyay, & Sil, 2003). Gupta and Singhal (2004), in their review article about perceptions of disability in some sections of the Indian community, observed that parental expectations for their child with a disability were mostly negative and unrealistic. In addition, cultural beliefs about causes and course/duration were found to play a key role in defining the parents' perceptions of their child's disability. Beliefs in the concepts of *karma*, God's will, fate, and destiny are common in both traditional and current Indian society, and serve as important

determinants of many events in one's life, including illness and suffering (Dalal, 2000; Gupta & Singhal, 2004). In Hinduism, the concept of *dharma* refers to the traditional established order, including all individual, moral, and religious duties (Dhruvarajan, 1993). The fatalistic approach of many Indian/Hindu families to life and its many challenges often stem from the underlying beliefs in one's *dharma* and *karma*. The theory of *karma* can be explained in terms of Newton's third law: every action has an equal and opposite reaction. In terms of the concept of *karma* in Hinduism, which also believes in the concept of multiple lives and reincarnation, good and bad deeds accumulate over all of one's previous lives and, if people have done something wrong in their present or previous lives, then they have to face the consequences (Dalal & Pandey, 1999; Kohli & Dalal, 1998). It would then be the parents' *dharma* to unreservedly accept the situation and take on the responsibilities of caring for the child. The Western approach of individual human rights is in stark contrast to the philosophy of *dharma* and *karma*, where the focus is on adjustments rather than rights (Dhruvarajan, 1993). Therefore, parents of children with disabilities in India tend to expect a life of sacrifice and adjustment rather than focus on rehabilitation for the particular child (Dalal & Pandey, 1999; Kaul et al., 2003).

Children with disabilities in India, especially rural India, are instinctively loved and cared for regarding basic needs, but parents often are not aware of the importance of early stimulation and early intervention (Gupta & Singhal, 2004; Kaul et al., 2003). They follow traditional parenting practices, and most of their support comes from within the family. At this juncture, it is important to note that there is tremendous heterogeneity in religious and spiritual beliefs and practices across different regions and groups in India, and factors such as socio-economic status, education levels, access to formal and informal support for families and their children with disabilities, place of living (e.g., city or village), support from immediate and extended families,

and personal practices of faith, etc., all have a significant impact on families' beliefs about disabilities and their hope and expectations for their child with a disability. Thus, it is crucial to consider the demographics of the participants in various studies published from India and/or on Indian people or societies as cultural groups, and care must be taken to not over-generalize such research findings. Families in India vary from the most educated, technologically advanced, and medically sophisticated consumers in the world to families with no education, the humblest of living conditions, and little connection to the modern world. Both kinds of families love their children and give the best care they know how to provide, but their children's lives and opportunities will be vastly different.

Resources for Children with Disabilities in India. Legislative protection for children with disabilities in India was not afforded until the passage of the Persons with Disabilities (Equal Opportunities, Protection of Rights, and Full Participation) Act in 1995 (de Souza & Patel, 2003), mainly as a result of parent advocacy groups. However, this constitutional right has not always translated into definitive action at the level of intervention services, facilities, and financial assistance for children with disabilities (de Souza & Patel, 2003). For example, according to Kalyanpur & Gowramma (2007), although the Indian government claims to have developed inclusive education programs for children with disabilities, the infrastructure and the quality of services are poor. Families are dissatisfied with both public and private schools. There is a general perception that government-funded schools offer a poor quality of education, while mainstream private schools do not offer what is needed for children with disabilities; some private schools may also refuse to educate students with serious needs. It is mainly the domain of non-governmental organizations (NGOs), primarily in the form of special schools, to provide service to children with disabilities. Most middle-class, educated, urban parents prefer placing

their disabled children in special schools, even though they are not fully satisfied with the services these schools offer (Kalyanpur & Gowramma, 2007).

Within the gamut of childhood disabilities, greater attention and rehabilitative care has been provided to children with physical or overtly visible impairments and disabilities (e.g., visual impairment, deafness, severe intellectual disability), while less conspicuous developmental disabilities such as autism and learning disability often remain undiagnosed and underserved (de Souza & Patel, 2003). Recent estimates suggest that over 94% of children with disabilities in India do not receive any educational services (National Sample Survey Organization, 2003). While various demographic and economic factors affect service provision to children with disabilities, involvement of parents in their child's education is primarily viewed in terms of supplementing the teacher's role as trainers and educators (Gupta & Singhal, 2005; Kalyanpur & Gowramma, 2007). The limited research conducted in this area indicates that families are mostly forced to care for their child with a disability without any professional or technological support, or to spend considerable amounts of their own time and money in seeking services (Kalyanpur & Gowramma, 2007; Gupta & Singhal, 2005).

Parent-Professional Relationships in India. Families can feel frustration about the difficulty in getting their children what they need. According to Kalyanpur & Gowramma (2007), their difficulties stem from negative professional attitudes toward children with disabilities, professional-dominated relationships in an environment that can sometimes be unsupportive of parents' rights, and a limited infrastructure for serving special educational needs (Kalyanpur & Gowramma, 2007). Unlike the US, there is no legislation in India that mandates parent participation in the process of intervention planning for their child, and there are no societal norms that accept or expect parents to advocate for their child. In a focus group

conducted with South Indian mothers of a child with a disability, Kalyanpur and Gowramma (2007) found that mothers had an implicit understanding that a parent could not be a professional. For example, the authors report that mothers in their focus group would frequently use self-deprecatory comments such as “after all, we are only the parents,” and came in with the initial assumption that the professionals would talk and lead the meeting while they would simply listen. There was a clear divide between the role of professionals and parents, and the professional’s authority is automatically assumed (Kalyanpur & Gowramma, 2007).

Autism in the Indian Context. It was not until the 1999 passage of the National Trust Act by the Rehabilitation Council of India that autism spectrum disorder was first recognized as a separate and valid diagnosis of childhood developmental disability; prior to this, children with autism were mostly diagnosed with intellectual disability or were eligible to receive assistance from the government only if they had a diagnosis of intellectual disability in addition to autism. (*Action for Autism: Autism Society of India, n.d.*).

Limited research has been done on autism spectrum disorders in the Indian context. However, of all the developing countries in which autism has been described, India has by far the largest literature on the disorder (Daley, 2002, 2004). Daley (2002) observes that over 50 articles and chapters on infantile autism had appeared in Indian publications and by Indian authors since 1962. According to Malhotra & Vikas (n.d.), the notion that autism is rare or non-existent in India as asserted by Sanua in 1984 probably stems from the fact that there are no published data on the prevalence of autism spectrum disorders in the general population. Although a limited number of studies have calculated childhood psychiatric morbidity in the general population, no data have been reported on the prevalence of autism spectrum disorders (Malhotra & Vikas, n.d.). Based on existing evidence from various clinic-based and retrospective studies in India

(Malhotra & Chaturvedi, 1984; Malhotra & Vikas, n.d.; Singhi & Malhi, 2001; Srinath, Chowdhury, Bhide, Narayanan, & Shivaprakash, 1989), it appears that the prevalence rate of autism in India is identical to that reported internationally. According to recent estimates by the Autism Society of India, *Action for Autism*, approximately 2 million children in India are identified as having an autism spectrum disorder. According to *Action for Autism*, while the disorder is not rare, a majority of the individuals on the spectrum in India have not been diagnosed and do not receive the services they need. A variety of factors, including lack of awareness and misunderstanding about autism among the medical professionals leading to misdiagnosis or under-diagnosis, are hypothesized to be main reasons for this diagnostic disparity (Daley, 2002).

Daley (2004) noted that while the literature suggests that medical professionals and families maintain a variety of beliefs and practices, no single view of autism has emerged from within India. Based on a study conducted with 95 families of children with autism in 4 major cities of India, Daley (2002) reported that “beliefs about etiology reflected a range of explanations, with no single preferred model of cause, but which included biological, structural or organic as well as environmental and psychological explanations” (p. 538). Lack of social relatedness was the most common symptom first noticed, and the identification of a problem behavior among Indian parents occurred an average of seven months later than in the US (Daley, 2004). The meaning attributed to a particular symptom is also likely to vary. For example, in her study, Daley (2002) found that “parents of a three-year old described their daughter as ‘mature’ because she preferred the company of adults to children, and a father believed his son was ‘dull-headed’ rather than autistic” (p.539). High-help seeking behavior has been noted among south-Asians (Dhillon & Srivastava, 1986). According to Daley (2002), help-seeking behavior in

Indian families is further intensified by the existence of multiple systems of medicine available in India, such as the Allopathic (Western), Ayurvedic, Homeopathic, and Unani traditions. Daley also reported that the presence of a child with autism may strengthen family bonds and interconnectedness. For example, as per Daley (2002), many Indian families “chose to have another child after their child with autism for the explicit purpose of having someone to care for the child with autism after the parent’s death” (p. 541)

Autism in Indian Families: A Pilot Study. We conducted a prior study with parents from India who have a child on the autism spectrum about their perspectives on their child’s disability. The study included questions about parents’ beliefs about causes of autism, choice of treatment procedures, role of extended family members in the child’s life, and acculturation (Ravindran & Myers, in press). All participants ($N=24$) lived in countries outside India, including the United States, Kuwait, and Canada, and responded to an online semi-structured questionnaire. Findings from the study indicated that most parents endorsed beliefs popular in their host cultures regarding causes of autism spectrum disorders, including immunizations and various combinations of genetics, environmental toxins, and biological factors. When specifically asked about culturally-Indian beliefs, about half the parents endorsed one or more traditional Indian beliefs in *karma*, destiny, and parental mistakes in present or past life. Although two-thirds of the participants in the survey reported that they did not use any traditional Indian treatments at that time (e.g., Ayurveda), about half the participants reported that they would prefer a combination of Western and Indian practices, if these were made available. Most parents reported that their child’s grandparents played only a minimal role in the child’s life, primarily because the grandparents lived in India and would only see the child once a year or once in two years during family visits. These parents reported that grandparents would

play a more significant role if they lived close-by or with the child and his/her family. These well-educated Indian-born parents presented perspectives of autism familiar to Western families, while about half also held beliefs that were inclusive of both Western and Indian viewpoints about having a child with autism. Parents did not volunteer information about traditional beliefs and practices until specifically asked. This highlighted the need for professionals serving culturally diverse families to become familiar with the cultural practices of the families that they serve as well as to ask culturally relevant questions during their interactions.

Findings from the pilot study informed the objectives of the current study and provided the framework for several of the research questions explored here, such as Indian families' beliefs about causes and treatments, approaches to intervention, and parents' relationship with the professionals who work with their children. The investigators were curious to explore in more depth the culture-specific themes and beliefs that would emerge if such a study were conducted in India, where families' experience of raising a child with autism is fully immersed within the surrounding context of the Indian culture. In addition to exploring family perspectives, the investigators sought to gain understanding of the kinds of facilities and services currently available for children with autism in a large southern Indian metropolitan city, the role of parents and professionals in selecting treatments and providing care for children identified with an autism spectrum disorder, and the nature of parent-professional relationships.

Statement of the Problem

The current study examined the perspectives of parents and professionals in a large city in South India about autism spectrum disorders. Specifically, the study examined parents' and professionals' beliefs about causes of autism, treatments and services used, and the nature of parent-professional relationships in managing a child's disability. Apart from some available

studies that have been conducted with families in northern Indian states such as Punjab and New Delhi (see Daley 2002, 2004; Karande, 2006), there is a dearth in existing literature about autism spectrum disorders in the context of Indian culture. Thus, it was valuable to conduct such a study in a large metropolitan southern Indian city. The study was comprised of personal interviews with participants using a questionnaire containing open-ended and semi-structured questions. The study's methodology was primarily qualitative and, as such, more exploratory than hypothesis-driven. Specific aims of the study included gaining better understanding of: (a) parents' and professionals' beliefs about causes of autism spectrum disorders, (b) choice of treatment procedures and parents' and professionals' expectations from these treatments for the child's future, (c) roles of parents and professionals in selecting treatments for a child with autism, and (d) the nature of parent-professional relationships. Additional questions about the role of extended family members in the child's life and each family's unique perspectives and experiences of raising a child with autism were also included in the interviews but are not treated here.

Research Questions

1. What do these families and professionals think causes autism spectrum disorders?
2. Once a diagnosis has been received, what services and treatments do the children receive?
3. What kinds of traditional healing methods unique to the Indian culture, if any, do parents and professionals use with children with autism?
4. What are the parents' and professionals' expectations from the treatments?
5. What roles do parents and professionals play in selecting treatments for children identified with autism spectrum disorders?

6. What is the nature of the parent-professional relationship with regard to a child's autism spectrum disorder?

Research Design

The goal of qualitative research is to describe, interpret, and understand a phenomenon of interest (Kazdin, 2003). The current study utilized qualitative methodology to: (a) explore parent and professional perspectives on autism spectrum disorders in the context of the Indian culture, (b) capture the richness of parents' and professionals' broad experiences of raising and/or working with a child on the autism spectrum, and (c) gain better understanding of the *essence* of parent-professional relationships in the realm of childhood developmental disability in the southern Indian city where data were collected. A qualitative research design informed by phenomenology (Husserl, 1970) was determined to be the most appropriate approach for the current study. Husserl (1970) described phenomenological research as one that aims to describe rather than explain and starts from a perspective that is free from hypotheses or preconceptions. According to Patton (2002), the foundational question of phenomenological research is: *What is the meaning, structure, and essence of the lived experience of this phenomenon for this person or group of people?* This question served as the foundational framework for the current study, where the phenomenon of interest was the "lived experience" of parents of children with autism spectrum disorders and the professionals serving these children and their families, within the context of the Indian culture. The study focused on exploring how parents and professionals in India understood and experienced the phenomenon of raising and/or working with a child on the autism spectrum, and understanding the nature of parent-professional partnerships in the context of childhood disability in the Indian culture.

The present study offered several valuable areas of contribution to current literature. First, given the dearth in existing literature about autism spectrum disorders in the Indian context, the current study's utilization of qualitative methodology to increase understanding of Indian parent and professional perspectives on autism is valuable. The qualitative design enabled gathering data that were rich in detail and embedded within the surrounding context. Qualitative research is also well-suited for development of theory that is grounded in the experiences of parents and professionals (Creswell, 2007; Morse & Field, 1995; Patton, 2002). The current study's focus on a metropolitan southern Indian city is unique. This is a region whose rapid growth in the area of developmental disabilities, particularly autism, even within the last five to eight years has been notable. Thus, the study makes a significant contribution about a less-researched geographical region in India in terms of autism spectrum disorders.

Further, hearing the participants' voices on issues related to beliefs and practices about autism spectrum disorders may help interventionists to design programs that better meets the needs of Indian parents and professionals from a 'bottom-up' framework rather than a 'top-down' framework. Such a process can foster credibility of diagnostic and intervention programming and enhance cultural and contextual relevance (Kazdin, 2003; Patton, 2002).

Finally, the current study contributed to the literature through its joint focus on parent and professional perspectives, both independently of one another, as well as in terms of the broader parent-professional collaboration in one city in South India with regard to a child's autism. Given the importance of parent-professional partnerships in effective management of child development in general (mesosystem; Bronfenbrenner, 1994), and a child's disability in particular (Dempsey & Keen, 2008), it is important to improve our understanding of how this crucial relationship is shaped by cultural and other factors in various parts of the world

(macrosystem). Such knowledge may help to improve parent-professional communication (Dempsey & Keen, 2008; Ravindran & Myers, 2011; Skinner & Weisner, 2007), development and implementation of interventions that are sensitive to the needs of the child and their family, and consequently, to an improvement in treatment outcomes for children with disabilities (Dunst & Dempsey, 2007).

Method

Participants

Twenty one professionals working with children with autism spectrum disorders and 19 mothers of children (16 years or younger) with an autism spectrum disorder participated in the study. Most mothers ($n=18$) and professionals ($n=17$) were recruited from four different 'special schools' serving children with autism in the city; two other professionals and one mother were recruited from an early intervention center based in a large privately-funded multispecialty hospital/medical college. In addition, two physicians (one child psychiatrist working in a large state-funded pediatric hospital and one developmental pediatrician in private practice) participated in the study. Participants were recruited with the assistance of the principals and directors of the four special schools and through contacts established by the student investigator.

Professionals. Professional participants (12 females) ranged in age from 24 to 56 years ($M = 35.04$ y; $SD = 8.15$), and spanned a range of disciplines, including special education ($n=6$); occupational therapy ($n=3$); speech and language pathology ($n=2$); social work and rehabilitation counseling ($n=3$); yoga, naturopathy, and siddha medicine ($n=2$); clinical psychology ($n=3$); child psychiatry ($n=1$); and developmental pediatrics ($n=1$). Of these 21 participants, five served as the director or co-director of their respective schools. Seven professionals held Bachelor's degrees, 12 held Masters ($n=10$) or Advanced Masters ($n=2$)

degrees, and two professionals had an MD. Professionals reported being in practice for 2 to 30 years in total ($M = 10.57$; $SD = 7.16$) and 2 to 30 years working with children on the autism spectrum ($M = 6.76$; $SD = 5.97$). In addition to their Bachelors, Masters, and/or other professional degrees, eight participants had specialized training through one or two year Diploma courses in autism spectrum disorders and other developmental disabilities.

Parents. Mothers ranged in age from 25 to 43 years ($M = 34.05$ y; $SD = 4.26$). Seventeen mothers were Hindu, one Christian, and one Muslim. One Hindu mother specifically identified herself as hailing from the Fisherman Community caste. Eleven mothers held a Masters ($n=10$) or Advanced Masters ($n=1$) degree, and four held a Bachelor's degree. Two mothers reported completing some high school (1 to 2 years) and two mothers reported that they had completed some schooling (8th grade or lower). Fifteen mothers were stay-at-home parents, although some ($n=9$) reported that they worked before having children or prior to their child's diagnosis. One mother worked as a special educator in her child's school and three volunteered full- or part-time in their children's school. With the exception of one mother who was divorced, all other parent participants were married. Ten mothers reported that they had only one child; others reported having two ($n=7$) or three ($n=2$) children, including the child with autism.

Family. The one divorced parent did not provide any demographic information about her former spouse. Spouses of the 18 mothers who were married ranged in age from 30 to 44 years ($M = 38.05$; $SD = 3.73$). A majority of fathers held a Master's degree ($n=11$), while others held a Bachelor's degree ($n=3$) or had attended at least one or two years of high school ($n=4$). Most fathers worked in well-paying jobs in a variety of positions and disciplines, including administrative, managerial, or banking ($n=6$), engineering or information technology ($n=5$), and consulting ($n=3$). Four mothers stated that their husbands were lower level laborers or temporary

workers in low-paying jobs. Family income generally ranged approximately from Rs. 3,000 to Rs. 2,50,000 a month (2012 exchange rate conversion estimates = ~ \$59.70 to \$4975 per month; conversion based on Purchase Power Parity (PPP) = ~ \$200 to \$17000 per month). Data about family income is not reported here in more detail since most parents felt uncomfortable sharing this information and believed that it was culturally inappropriate to talk about money and wealth.

Family Structure. Sixteen mothers described their family set-up as “nuclear.” Of these 16 participants, 12 mothers reported that they lived with their spouse and children, while 4 reported that they lived with their spouse, children, and parents or in-laws. Three mothers, including the mother who was divorced, reported that they lived with their children and the maternal grandparents; the two other mothers reported that their husbands worked abroad and sent money home for their child’s treatment and managing their family’s expenses in India.

At this juncture, it is important to provide a context and describe the contrast between the two families whose husbands lived abroad, and the reasoning for why these two participants had family structures that were different from the cultural norm. Of the two participants, one mother reported that her husband was a software engineer, held a high-paying job in the West, and was able to visit his family and child at least once or twice a year. She also stated that her son was diagnosed and received early intervention services abroad, and that she had moved recently to South India in order to *see what else is out there* (parent quote) in terms of services for her son. This mother planned to spend a few years in India educating her son in the special school that he was enrolled in, provide him with more socialization opportunities with close-knit family, and then move back abroad with her son to rejoin her husband.

The other parent stated that her husband lived in the Middle East and had started working there 12 years ago, prior to their marriage in 2000. He visited India briefly for their wedding, and

returned to his job in the Middle East 40 days after their wedding. He worked as a low-level laborer in a printing press, and was only able to visit his family briefly every two to three years due to constraints related to finances and the amount of vacation time that he was allotted at work. The mother reported that the first time her husband was able to visit India to meet their son (9 years old at the time of interview) was when the child was 18 months old. She stated that her husband had kept his job abroad since it paid better than jobs that he would find locally in the southern Indian city where they lived, but that they were still very limited in terms of financial resources. In addition to her husband sending money each month for her child's treatments, this mother stated that her father helped financially and in other ways with caring for her son. According to this mother, her husband sent most of his earnings to his family in India, and was only able to speak with his wife on the phone every other week. She stated that they hoped that he would find a job in India and would be able to move back to his family, although she was not hopeful that their financial situation would improve very much.

Financial Management of Child's Disability. In general, families in India did not receive much financial assistance from the government, with the exception of lowered fare on Indian Railways travel, a small income tax credit, and a stipend of Rs. 500 a month (PPP conversion = ~ \$50/mo), if the disabled individual or their parent is able to present a valid National Disability Certificate and ID Card issued by the Department of Social Welfare, Government of India. In the absence of this card (which was more the norm than the exception), most families paid for services out of pocket or with help from their extended families.

Child. All child-related information, including diagnostic and treatment history, was obtained through parent-report. The investigators did not meet any of the participants' children, review their medical charts, or seek to confirm diagnosis through direct or indirect assessment.

As gathered from parent-report, children of parent participants in the study (13 boys, 7 girls) ranged in age from 4.5 to 15 years ($M = 8.39$ y; $SD = 2.94$); one mother referred to both her twin girls with autism when speaking about her experiences throughout the interview, and thus information about both of her daughters were obtained. Eighteen children were diagnosed in India, and two were diagnosed in two different Western countries. Eighteen children had a primary diagnosis of autism spectrum disorder, including Autism, High Functioning Autism (HFA), and Pervasive Developmental Disorder-NOS (PDD-NOS). Two children were reported to have a primary diagnosis of Attention Deficit Hyperactivity Disorder (ADHD) and a secondary diagnosis of an autism spectrum disorder. Of the 18 children who had a primary diagnosis of ASD, 8 had additional diagnoses such as ADHD ($n=3$), Intellectual Disability ($n=2$), Cerebral Palsy & Epilepsy ($n=1$), Deafness & Vision Impairment ($n=1$); and Anxiety Disorder ($n=1$). Severity of impairment is not reported, since information was obtained through parent-report, and we did not corroborate or assess this information through other means such as direct evaluation of the child. The age at which children were diagnosed with autism ranged from 1.5 years to 8 years ($M = 3.075$; $SD = 1.45$). Diagnosing professionals ranged from child psychiatrist ($n=4$), neurologist ($n=4$), pediatrician ($n=4$), interdisciplinary team at special school ($n=4$), autism specialist ($n=2$), and physiotherapist ($n = 1$).

Settings

Data were collected primarily from four different special schools and one hospital-based early intervention center in a large, metropolitan southern Indian city. In addition, a developmental pediatrician and a child psychiatrist were interviewed in their offices housed in a private practice and a large state-funded pediatric hospital, respectively.

Funding and Fees. Three special schools were privately funded through corporate and other non-governmental organization sponsorships, personal donations, and a *nominal tuition* (direct quote) charged from families for their children's services and education. Although the directors did not specify what their fee structure was, tuition was estimated to likely range from about Rs. 800 to Rs. 2000 a month (PPP conversion = ~ \$50 to \$200 a month). The early intervention center was the only one of its kind in the city, and part of a large, privately funded multispecialty hospital/medical college; parents enrolled in this center were charged Rs. 800 a month for services. The child psychiatrist who worked in the state-funded pediatric hospital and the one school that was federally funded provided free comprehensive services to all children and families. Families that were seen by the developmental pediatrician in private practice paid out of pocket and were charged anywhere between Rs. 15,000 to Rs. 30,000 (PPP conversion = \$1000 to \$2000) based on the *treatment package* (direct quote; package included diagnostic workup, speech, OT, and diet-based interventions, and follow-up visits every three months) that they selected for their child.

School 1. School 1 was established by the Government of India and serves as a national resource center for individuals with disabilities. Unlike most resource centers and special schools in the city and other parts of India, School 1 served individuals with multiple disabilities, including visual, motor, and hearing impairments, intellectual disabilities, and other developmental disabilities. School 1 was located amidst plenty of shady trees and easy access to a beach. It was housed in a renovated concrete building with a large open layout for various classrooms, office space for therapists, and administrative offices, with plans for a larger, state-of-the-art building. The open room structure was separated by dividers between various classrooms and office spaces, and thus the noise level in the building was fairly high. A number

of people, including parents, children, and staff, were observed to mill around, and the place felt both busy and calm. The adult rehabilitation unit was housed in a separate building on the same campus and included vocational training units such as tailoring and embroidering for adults with disabilities and mothers of children with disabilities.

The school prided itself as one of the few truly interdisciplinary government-funded resource centers providing free services for children and adults with disabilities. Departments housed in the premises included Special Education, Rehabilitation Psychology, Speech and Language Pathology, Physiotherapy, Physical Medicine and Rehabilitation, Adult Independent Living, Community Rehabilitation, and other administrative departments. School 1 was committed to providing training opportunities for their staff and offered one-year diploma and certification courses in areas such as autism spectrum disorders, cerebral palsy, hearing and visual impairments, prosthetics, and orthotics.

In terms of clinical services, School 1 served about 80 children with multiple disabilities. Of these 80 children, 20 to 25 had a diagnosis of autism and some other disability, usually intellectual disability. According to the director of the school, the largest number of children had cerebral palsy and intellectual disability, and the next largest group was children who were visually impaired and deaf. School 1 provided free comprehensive services for all individuals seeking enrollment, including interdisciplinary assessment and diagnosis for a variety of disabilities, family-based intervention and support, early intervention for children younger than three years of age, early childhood special education for children younger than six years of age, special educational for elementary and secondary age students, vocational rehabilitation services for adults with disabilities, and community outreach. The school's model of service delivery was inclusive of family in that mothers, especially of young children, were encouraged to observe

and participate in implementation of treatments at school, and to continue practicing treatment strategies at home. In order to lower their anxiety, mothers were often paired with different children in the school and seldom worked with their own. The school also ran a number of free special clinical services in neurology, ophthalmology, dentistry, and psychiatry for individuals that they served in the school. These special clinics were made possible by School 1's collaboration with other health care providers in the community, medical and dental hospitals and colleges across the city, and specialized community clinics. In addition, School 1 provided free transportation to and from the school every day for the children, mothers, and adults attending the different programs, and offered on-site accommodations for up to one month for families visiting from other states in India to avail of their clinical services. In addition, the school helped to empower mothers by teaching them job skills and helping them to obtain bank loans to start a small business after their 6-month vocational training in tailoring and embroidery. A majority of individuals enrolled in School 1 were from the lower middle and lower socio-economic strata of the society.

School 2. School 2 was funded through a registered Trust and depended for the most part on corporate and personal donors and sponsorships. In addition, School 2 operated as a fee-for-service facility, and parents paid for services out-of-pocket. School 2 served families from a variety of SES groups and provided financial assistance and subsidies for families from lower income groups, if needed. In the school director's words, *No one is turned away because they can't pay for it. We will somehow try to make it work.* School 2 had two separate buildings; one devoted to a more formal school-based approach to intervention for autism, and one devoted to traditional Indian practices such as Yoga and Ayurvedic massage.

The school's model of service delivery was inclusive of family in that professionals actively sought parent engagement in the treatment process, helped them to understand how to implement home programs, and engaged in consistent and open communication with the parents on a regular basis. The directors were especially committed to establishing a trusting alliance with the families, and appeared sympathetic and collaborative in their approaches and treatments. During our visits, School 2 was quiet with little activity (we usually visited in the afternoons, when the children were in the other building), but the place felt calm and people were welcoming and cooperative.

School 2 was devoted to promoting a holistic approach to autism intervention and specialized in a variety of traditional Indian "naturopathy" based treatments such as Siddha, Ayurveda, and Yoga. The school was run by young professionals who had naturopathic backgrounds and professional degrees in Siddha Medicine (director 1) and Naturopathy and Yogic Sciences (director 2).

As gathered from the interviews with the co-directors of the school and the official Indian Naturopathy website (www.naturopathy.co.in), Naturopathy is based on the premise that *all healing powers are within one's body and thus treatment-strategies are focused on promoting and enabling health through the body's natural healing powers* (quote from director). Specifically, Naturopathic science believes that "since we fall ill only when we go against nature, the cause of diseases (toxins) is expelled from the body to cure it" (www.naturopathy.co.in). Naturopathic forms of medicine strive to maintain the healthiness and well-being of one's immune system "both psychologically and physically" and consider the immune system the core center of our wellness and our ability to heal and maintain health. One of the other core premises of Naturopathic approaches is also that the therapies used to support and stimulate this healing

power of nature must be in the “gentlest, least invasive, most efficient manner possible” (www.naturopathy.co.in). Rather than simply focusing on symptom-alleviation, treatment is focused to diagnose and treat the cause, and thus there is heavy emphasis on treating and “expelling” the root cause of the disease or disorder. To accomplish these goals, Naturopathic medicine incorporates many therapeutic modalities such as herbal medicine, homeopathy, nutrition, hydrotherapy, food, exercise therapy, physical therapy, manipulation of the bony and soft tissues, lifestyle changes, and counseling.

Siddha Medicine, in particular, is a traditional Indian treatment that originated in South India and dates back to thousands of years. It is considered a form of Complementary and Alternative Medicine (CAM) in the mainstream Indian society that follows a more traditional allopathic medicine model based in Western medicine. As per one of the directors of the school, Siddha has *good literary evidence* and is considered an evidence-based medicine. The focus of Siddha medicine is on establishing harmony within the body’s multiple systems and organs, such as the immune system and digestive tracks. As noted by the directors, treatment is often based on *body constituency of an individual and is aligned with natural powers and changes that occur within one’s body based on the time of the day and the foods that they generally eat.*

As per the co-directors, Naturopathy and Yoga as well as Siddha Medicine, as Indian systems of medicine, fall under the Department of AYUSH (Ayurveda, Yoga, Unani, Siddha, Homeopathy), Ministry of Health & Family Welfare, Government of India. As defined in the official government website (www.indianmedicine.nic.in), the primary aims of the Dept. of AYUSH is to promote “focused attention to development of Education & Research in Ayurveda, Yoga & Naturopathy, Unani, Siddha and Homoeopathy systems.” The department offers 5½ year

degree courses in Bachelor of Naturopathy and Yogic Sciences (BNYS) and Bachelor of Siddha Medicine and Surgery (BSMS).

At the time of data collection, School 2 had a total enrollment of 19 children that were split by age and level of functioning into five different groups. Each group was focused on different skills such as adaptive living, academic skills, communication skills, behavioral skills, and a more general group addressing specific needs of each individual child. We did not observe any treatment sessions in progress. However, based on the directors' report, in addition to offering traditional Indian medicine and healing practices to children with autism such as Siddha, Ayurvedic massages, and Yoga, School 2 offered more "mainstream" disability intervention services. These included services such as special education for children with autism based in *Verbal and Applied Behavior Analysis approaches; computer education; occupational therapy services for tactile, vestibular, and proprioceptive functioning; hand functioning skills such as clay and mud therapy; and sports therapy such as group play, roller skating, and any other active play that provides more outlets for children to expend their energy than engage in behavior problems* As per the directors, the school also offers Auditory Integration Therapy for children who need it to *calm overall behaviors, reduce hyper-acute and/or painful hearing, and reduce irritability, impulsivity, and restlessness*. Most children enrolled in the school received all forms of services at different times, based on their progress, including the traditional Indian treatments that the school offered.

School 3. School 3 was located in one of the more affluent, busy residential neighborhoods of the city. The school charged tuition and fee from parents for their child's school enrollment, as well as relied on the *trustees of the organization, corporate groups, individual donors, and our friends*. For families who could not afford to pay the tuition and fees,

the school relied on individuals or trustees of the school to sponsor those children. The school itself was housed in a converted home with several small to medium-sized rooms, and a large, covered porch in the front and the back of the building. A medium height cement compound wall ran through the whole perimeter of the school, and an iron grill gate served as the entrance. One “watchman” (security guard) was present on the premises throughout the school day, and kept an eye on the children and prevented them from wandering off of the premises. The school gates remained locked throughout the school day, except for when needed (e.g., pick-up and drop-off times in the morning and evenings, staff outing with the children etc.). The school was shaded over by many large trees and felt calm; however, there was still the distinct feel of constant motion and activity within the school premises, and the sound of traffic from the main roads a few streets away was palpable.

Despite the relatively small size of the actual school building and classrooms, the large number of students enrolled in the school was striking. The director reported that about 110 children attended the school full-time and received school-based services at this site. Of the 110 children, 100 were identified as having an autism spectrum disorder, while the remaining had a diagnosis of ADHD. In addition to this site, the school had another premise in a different location where they served 85 children with Learning Disabilities. According to the director, although they served a variety of families from different income levels, most children came from: *low income or lower- and upper middle class families, very few high society people.*

Children in the school ranged in age from four to 15 years, and were served by a wide variety of school staff, including occupational therapists, speech therapists, special education teachers, and physical education teachers. The director described the school’s intervention curriculum in the following way:

Basically here we work with three main areas: one would be special education. We use, in special education, it is a very eclectic approach. We don't have any one particular therapy as in we don't follow only the TEACCH or only the ABA... it is very very eclectic approach. A lot of emphasis on academic work. Because we feel that it is a strength of children with autism. They have a lot of positives. The academic area is very very strong. So, we believe that if we push their strengths to overcome their weakness, and not only focus on their weakness, which is communication and social skills. Apart from that, we give OT, which takes care of their SI [sensory integration], and speech therapy, which takes care of their communicational aspects. But, all that is incorporated in their class situations also. We do give OT in the class, we do give speech therapy in the class. And, along with that, we have other areas. We have Yoga, we have skating, we have music, dance, cooking, art and craft...

Treatment goals and strategies were decided based on each child's specific needs, level of functioning, age, and parent concerns. While special education and occupational therapy was provided to all children enrolled in the school as part of their tuition and fees, parents paid extra for additional services such as speech therapy and yoga or extracurricular classes such as skating and dance. The school maintained a high level of regular, daily communication with families about their child's progress and made every effort to include the family in the treatment decision making and implementation process. However, the director of the school usually had the ultimate say in terms of what kinds of services to provide each child once they were enrolled in her school, based on her assessment of the child's abilities and challenges.

School 3 was one site where we actually had the opportunity to observe some of the children casually, although we did not see the children in any structured settings (e.g., therapy session or classroom time). The following is a verbatim excerpt from the field notes of the two investigators after the end of our first day at School 3:

Several parents were waiting with children outside the school for an appointment or to pick up or drop off their kids. Many parents were holding/carrying their [younger] children while waiting. Parents appeared extremely patient. None of them were observed to scold or harshly discipline the children even when the child [with autism] was screaming or throwing a tantrum. Rather, most parents were observed to either ignore the inappropriate behaviors or gently redirect. (Interviewer 1)

We observed a teacher leading a group of 12 children doing physical exercises on the covered patio. Children appeared to range in age from maybe four to 15 years; most seemed to be in the severe range of impairment. Some children followed the movements and joined in. One little girl just sat and did nothing. Two older boys engaged in repetitive motor mannerisms (waved fingers in front of eyes) the whole time. A small boy kept grabbing at the other children's legs, then ran away. He did not join in at all. At the end, when others went inside, he would not go. Another male (Teacher? Aide?) tried to talk him into coming, then held his hand and tried to pull him in. The child lay down and threw a tantrum. The teacher finally picked him up and carried him inside without speaking or saying anything to the child. Others paid no attention to him. (Interviewer 2)

School 4. School 4 was housed in a large, quiet, and aesthetic building. Parents paid tuition and fees for their child's enrollment in the school, and the school received additional funding from *close friends and private donations*. Families who were unable to pay for service were allowed to enroll their children for free, or the school tried to find someone to sponsor the child's education, if possible. For the most part, however, School 4's directors stated that no child was refused admission because they could not afford to pay for service. In terms of the physical facility, as is typical in Indian building structures, School 4 was secured on all sides by cement compound walls with a large iron gate serving as the entrance. There were large coconut trees in the front and back yards, and a small garden near the front entrance. The building was relatively new, and donated by a friend of the school's, and classroom design and layout was more open and spacious compared to some of the other sites that we visited.

School 4 served 17 children between the ages of 4 to 14 years from a *variety of backgrounds*; 13 were enrolled in their full-time program and 4 children in their part-time program. Children were organized by age and skill level in to three different groups: 4 to 6 years, 6 to 10 years, and 10 to 14 years. In terms of treatments provided, the school used strategies based on Verbal Behavior Analysis and focused on communication, play, adaptive skills, and social skills. While the younger children received more play-based and communication-based interventions, older children received interventions targeting functional adaptive skills and social

skills and social functioning in everyday life. The school also placed high emphasis on parent training and parent involvement in treatment, and engaged routinely in problem solving with parents regarding behavioral challenges and other issues. We were unable to observe any of the treatment sessions or see any of the children (due to the timing of interviews), and thus cannot speak in more detail about what some of these treatments looked like in practice.

The school's directors, one of whom was also a parent of a child with autism, were both extremely committed to raising awareness in the community about autism spectrum disorders. As noted by one of the directors, *when we started the school, we never wanted this to be a school setting or a major center with lots of children coming in and out, we were not trying to expand the setting and make this a big thing. We always thought that this would be only be a resource center and we would help others set similar schools in the community.* . . School 4 had conducted many public awareness programs on the topic and was widely recognized by other special schools in the city and other parts of India as a resource center for families of children with ASDs.

School 5. School 5 is an early intervention center housed in a large multi-specialty, private hospital and autonomous medical university. The early intervention center was established on hospital premises as a *service to the community*. The school was fully funded by the hospital, and parents paid a nominal fee (~ \$50) for service each month. The early intervention center had beautiful, bright classrooms with large open layouts and attractive wall-art throughout the building. In terms of infrastructure (e.g., high quality materials, large spacious classrooms, variety of toys and play-based learning materials for the children etc.), this center stood out distinctly as having a lot more resources compared to the other sites from where we recruited our participants.

In terms of their service delivery model, the professionals that we spoke with at School 5 identified the high level of focus on mothers' training and mother empowerment as being a unique feature. Mothers stayed with their children at school for the entire course of the day, and gained hands-on training in implementing treatment approaches with the children. In addition, because the center was housed in a large multidisciplinary hospital, parents and children had access to a whole range of interdisciplinary team members, as per their need. The parent's first point of contact to gain admission to the center was through the hospital's social worker, who would then make appropriate referrals to the other disciplines such as speech, occupational therapy, psychology, special education etc. based on the child's need. The intervention center served 80 children with a variety of disabilities, and about 25 of those children were identified as having an autism spectrum disorder. Classrooms were served by 11 total special educators, in a ratio of 1:8. As per the report of the speech pathologist that we interviewed at the site, the intervention started with 4 children and had grown to 80 children in less than five years.

We were able to visit School 5 only once to interview a parent and two professionals, and thus did not have the opportunity to observe any of the children in their classroom setting or gather more detailed and qualitatively rich information about this site.

Procedure

Recruitment. At the outset of the study's proposal, we obtained email confirmations from directors of two different schools for children with autism spectrum disorders in southern India about their willingness to participate in the study. Upon reaching India, these two directors were approached again in person, and they provided verbal consent to participate in the study. The directors of these two schools also helped to identify eligible families and professionals (e.g., therapists and special educators at their school) to participate in the study. In addition, they

helped the investigators establish contact with other special schools and professionals working with children on the autism spectrum in the city. One professional participant was also recruited from a large state-funded pediatric hospital in the city through contacts established by the student investigator. Flyers about the study were made available at the participating schools and professional offices, but this did not yield any participants. All participant recruitment occurred through direct invitation by the school directors to their parents and staff.

Interviews. Two interviewers, the student investigator and her faculty advisor, conducted the interviews. The student investigator is Indian by origin, was born and raised in the city where data collection occurred, and spoke the native language. In addition, she had two years' experience working with children on the autism spectrum in a different city in southern India prior to starting graduate studies in the United States. The faculty investigator is Caucasian by origin, born and raised in the United States, and has worked for many years in training students who provide early intervention to special needs children and in conducting research with families of children with autism spectrum disorders.

The investigators were rarely informed beforehand who their participants for the day may be. No list of participants was provided by the directors of the school. The informal and casual nature of the cultural set-up was reflected both in how the directors introduced us to the parent and professional participants only at the time of their interviews, and in how the participants always responded with enthusiasm and eagerness to freely participate. We were made to feel very welcome at each one of the sites, and were routinely provided with hot tea or coffee during the day as a sign of the school's hospitality. Each interviewer completed about three interviews per day on average.

Most participants were alternatingly assigned to the two interviewers based on interviewer availability at any given time, with the exception of participants who spoke no English ($n = 7$); these participants were assigned to the student investigator who was able to conduct interviews in the regional language as well. Alternated assignment was chosen to eliminate the possibility of interviewer bias (Kazdin, 2003). All 40 participants were interviewed in person by us over a four-week period, and both interviewers spent several full work days at each of the sites. All interviews were recorded on small, unobtrusive digital voice recording devices with the participants' consent. No identifying information was collected from participants, and participants were only identified by an assigned number.

Measures

A questionnaire was designed specifically for the purpose of this study, with separate versions for parents and professionals, based on the measure developed by the student investigator for the earlier pilot study used with Indian parents of children with autism (Ravindran & Myers, in press). Initial questions were designed based on the student investigator's experience and knowledge of the Indian culture and existing qualitative cross-cultural literature on autism spectrum disorders (Daley, 2002, 2004; Mandel & Novak, 2005). Questions were further refined to be culturally appropriate and relevant based on input from parents and professionals who were consulted for the pilot study and feedback obtained from the school directors of the current study at the time of recruitment. Since the study was qualitative and exploratory in nature, most of the questions were open-ended or semi-structured. Information about adult participant demographics (e.g., age, SES, education, ethnicity, religion) and child demographics (e.g., age, gender, diagnosis, etc.) were collected at the end of each interview as part of the interview process rather than as a separate measure filled out by

participants to reduce their burden. See Appendices A and B for complete parent and professional questionnaires.

Informed Consent and Confidentiality

To maintain participant confidentiality, no identifiers (name, DOB, telephone numbers) were collected during the interviews. No written consent was obtained from the participants since it is culturally unfamiliar and potentially culturally threatening to the participants to ask for written consent. A modified Statement of Consent was approved by VCU's Institution Review Board to obtain verbal consent from all participants at the time of interviews. However, it was notable that with the exception of the directors of the four different schools who briefly glanced at the Statement of Consent, all participants dismissed the formal reading of the Statement of Consent. In general, the consent process was fairly informal and all participants were eager, welcoming, and willing to participate in the study, and readily gave verbal consent. Regardless, participants were orally presented an abbreviated version of the Statement of Consent prior to beginning the interviews. They were informed of the purpose and nature of the study, assured that it was completely confidential, and that they had a right to decline participation, answer only as many questions as they felt comfortable answering, and/or discontinue when they wanted without offering any explanations. If they then agreed to participate in the study, this was considered their informed consent. No participant declined to participate after hearing the particulars of the consent process.

Coding and Data Analysis

Transcriptions, Field Notes, and Data Management. The first step in treating the data was to transcribe the digital recordings into written form and maintaining field notes. Both interviewers maintained field notes based on their observations and conversations at each of the

different sites; these notes were sometimes handwritten and sometimes typed on the computer. The interviewers discussed the day's interviews at the end of each day's work, and these discussions became field notes. Ultimately, all field notes were transferred to the investigators' password-protected laptop computer as Word documents.

The initial verbatim transcription of all the interviews was a long and tedious process. About a third of the interviews were transcribed on the same day by the same interviewer who had conducted the interview. Thus, in the late afternoon and evening after interviewing, the two investigators spent between 4 to 6 hours listening to the recordings and typing up transcriptions. Interviews were typed into Microsoft Word. To the extent possible, interviews were transcribed verbatim from the audio files. The audio files were often hard to hear due to background noise (e.g., children's voices, traffic sounds, construction noise etc.) and lack of clarity in speakers' voices; transcription often required listening to short phrases multiple times. Interviews that were conducted in one of the two native languages ($n = 7$) were translated by the native speaker student investigator to English and transcribed and checked for accuracy by the student investigator and a second native-speaker.

After the first transcription, the interviewer/transcriptionist went back through the recording, listening again and correcting any errors. Each investigator devoted about three to four hours on average toward checking and ensuring accuracy of the transcriptions. After this double-check by the first transcriber, the other investigator listened to the digital recording and made corrections, if needed, to the typed account. Each of the interviews was thus listened to and checked a minimum of three times. Some of the interviews were listened to additional times to clear up any words or phrases that were unclear. Not all the transcriptions were completed during the time in India. Back in the U.S., the student investigator conducted the initial transcription and

the second check of most of these, and the other investigator listened to the recording and conducted the third check. Besides the two interviewers, some of the recordings were transcribed back in the U.S. by two individuals who were trained for the job. These transcriptions were carefully checked by one or both of the original investigators. In addition to ensuring accuracy, this process enabled the coders to gain more familiarity and *immersion* with the data (Patton, 2002).

Similar to field notes, all transcriptions were stored securely as Word documents on both investigators' laptops as well as on portable flash drives for back-up security, and also entered in to the qualitative coding software (Nvivo 8) used in the study to code and analyze data. In addition to maintaining a secure electronic copy, all interview transcripts, totaling 624 pages, were printed for first-pass hand coding by the student and faculty investigators, and stored securely in folders.

Analytical Approach. Analysis of the transcribed interviews was a multi-step process that lasted several months. Data analysis was guided both by general approaches to analyzing qualitative data (Creswell, 2007; Morse & Field, 1995; Patton, 2002) and theory-based analytical approaches specific to phenomenological research (Creswell, 2007). The first step in analyzing qualitative data is to become extremely familiar with the data (Morse & Field, 1995). According to Morse and Field (1995), four cognitive processes are integral to this analytical process: *comprehension* (understanding the data and making sense of it), *synthesis* (getting a “feel” for the data, or having sufficient understanding or grasp of the data to be able to make generalized statements about the participants), *theorizing* (systematic selection and “fitting” of alternative models to the data), and *recontextualization* (generalizing the emerging theory to other settings and populations). These four processes are more or less sequential. For example, a reasonable

level of comprehension must be achieved by the researcher before being able to make generalized statements about the participants (or, synthesize), and a successful synthesis should enable formation of new theory based on the data. This was the foundational approach that was adopted to analyze data in this study. The process of comprehension and synthesis, as described above by Morse & Field (1995) were both initiated and refined through the process of personally translating, transcribing, and checking the transcriptions multiple times while listening to the audio taped interviews. Once sufficient “feel” for the data or *immersion* (Patton, 2002) was achieved, a more theoretically-driven and systematic approach to coding and analysis in the phenomenological framework (Creswell, 2007) was adopted.

Data were coded and qualitatively analyzed for emerging themes and constructs through inductive analysis (Patton, 2002). The content of the participants’ responses to the personal interviews, along with the interviewers’ field notes, were systematically analyzed for categories, patterns, and themes. To identify these categories, each response in this study was carefully segmented by topic (e.g. parent-professional relationship), that then became the primary categories (e.g. role of parents and professionals in selecting treatments). A thematic analysis was also conducted to identify the common themes and threads in participants’ responses across the study. Themes are often concepts that are *indicated* by the data, rather than being concrete entities, and thus an approach of stepping back and considering what the participant was “trying to tell us” (Morse & Field, 1995) was adopted. Continual refinement of themes and codes that emerged from multiple iterations of analysis ultimately led to the development of the “essence” of the studied topic and questions of interest (Creswell, 2007; Patton, 2002). Credibility of findings was enhanced by using methods of prolonged engagement, constant comparison, persistent observation, and audiotaped and verbatim transcription. Further, trustworthiness in

analysis and findings was promoted by using triangulation between investigators and with extant theory and research findings (Lincoln & Guba, 1985; Strauss & Corbin, 1998). Further, “thick description” (i.e., rich contextual description, including elaboration on participants, settings, and methods) of the research context and methods was also used to promote evaluation of the transferability of findings (Lincoln & Guba, 1985, p. 316). Finally, dependability and confirmability of the data and analyses was promoted through a comprehensive audit trail (Lincoln & Guba, 1985).

Coding. The student and faculty investigators, with 4 to 15 years’ experience in qualitative research, served as the primary and secondary coders for the study. A partnership approach between the investigators was adopted to code and analyze the data. Memoing about coding, analysis, and interpretation of data, as well as weekly two-hour long meetings and discussions between the two coders, were crucial and ongoing parts of the coding process (Strauss & Corbin, 1998). During the first-pass coding or *Open Coding* (Strauss & Corbin, 1998), the two coders, independently and together, worked on developing a codebook for possible categories, themes, and patterns (Patton, 2002). During this process, each coder first independently read through the hardcopy text of the interview transcripts, made margin notes, highlighted relevant statements, and came up with initial codes. The two coders worked together closely during weekly meetings to talk about the interviews and their respective and combined impressions of emerging themes and categories. For the most part, the two coders were in agreement about these themes and categories; in cases where there were differing interpretations, the two coders worked together to reach a consensus about the respondents’ answers and explanations (Patton, 2002).

During the open coding process, in addition to coding each response of every interview, the two coders analyzed each interview as a whole entity to come up with handwritten overall themes and notes about each individual participant. This process helped to ‘personalize’ the participants and provide better context and meaning to their unique experience of raising and/or working with a child with autism; in other words, it helped in developing the “essence of the phenomenon” (Creswell, 2007, p. 157).

Second Stage Coding. The memos, notes, and margin notes from the first-pass manual coding provided the framework for the second stage coding on Nvivo 8 (N8). Using the initial codes that emerged during open coding, each interview and response was re-coded on N8 in a more systematic manner. Specifically, statements from each interview were placed into the codes. In addition, the handwritten overall notes and themes on each participant were transferred to the N8 database and sorted into codes reflecting overall participant characteristics and tones of each interview. While the basic framework of codes, especially the broader categories (e.g., Beliefs about Causes, Role in Selecting Treatment etc.) remained consistent, using the software provided a method by which data could be organized better into themes and categories. The student investigator led this coding, with the faculty investigator serving as the secondary coder.

The first iteration of second-stage coding on N8 resulted in 22 total categories (11 parent and 11 professional codes) and 164 codes representing different themes that were clustered under the larger categories. Each of the codes and placement of statements was reviewed by the two coders working together and agreeing upon changes. These initial categories and codes were then combined and refined over multiple iterations, which ultimately resulted in a total of 19 categories (9 parent and 10 professional codes) and 97 codes. Of the final set of codes, 10 categories (5 common to parents and professionals, 2 exclusive to parents and 3 exclusive to

professionals) representing 57 codes and emergent themes were selected for analysis in this study. Thus, during meetings of the two coders, some codes were merged, some expanded, and some eliminated. This process resulted in consensus agreement that there was good support for each code. This led to writing a summary of the findings that included themes and exemplars of parent and professional statements that demonstrated the themes.

Expert Checks. Once the final coding structure was established, all the codes (with a randomly selected sample of exemplar statements under each code) were sent for “expert check” with two different persons from the groups represented in the study sample, namely, an Indian mother of a child with autism and an Indian professional working with children on the autism spectrum, both living in the United States. This procedure was adopted as a close alternative to a typical “member check,” which is directed at “judgment of overall credibility and ideally tested with members of the stakeholding groups from whom data were originally collected” (Lincoln & Guba, 1985, p. 316). Although logistical constraints prevented us from contacting the actual participants of this study in India, arranging for an expert check with two members of the same cultural groups and who were experienced in the same phenomenon explored in this study served to increase the overall credibility of the identified codes and thematic structure. In addition, the codes and exemplar statements were sent to two other experts in qualitative methodology with two to six years training and experience each, and this served to further triangulate the data and bolster trustworthiness and credibility of findings. With the exception of suggesting some minor changes to code names to more accurately describe themes reflected, the expert checkers were all in 100% agreement with the original coding structure and identified themes. Based on the feedback provided by the expert checkers, the primary and secondary investigators came to a consensus about the final names for the different themes that emerged from the data.

Findings

Overview

Qualitative coding of the parent and professional interviews ($N=40$) generated 10 broad categories and a cluster of 57 codes across categories representing themes that emerged from the data. Of the 10 categories, five were common to both parents and professionals (Beliefs about Causes, Decision-making about Treatments, Implementation of Treatments, Parent-Professional Relationship, and Autism in India), two were exclusive to parents (Satisfaction with Treatments and Services and Expectations for Child's Future), and three were exclusive to professionals (Report of Family Beliefs about Causes, Report of Family Expectations for Child's Future, and Views about Families). The coding clusters under each category represented descriptive themes of parents' and professionals' beliefs about autism (e.g., Don't know or Unsure; Genetics; Religious and Spiritual Explanations etc.), nature of parent-professional relationships (e.g., Positive, Collaborative, Trusting, and Open; Ambivalent or mixed; Directive, Professional-driven etc.), and the positive and negative processes and contextual factors associated with raising and/or working with a child with autism in South India (e.g., Society is understanding and supportive; Society is rejecting and critical; Problems with resources, expenses, and accessibility etc.). In addition, a separate category was created to account for the descriptions provided by both the parents and the professionals of treatments and services currently used with the children. However, in the following sections, this category is treated descriptively and in terms of frequency (e.g., how many people report using what kind of treatments) rather than thematically, since we did not observe any of the treatments being implemented with the children, and thus cannot describe in context or in any detail what these treatments were and how they were implemented.

Across the 10 categories, each theme was mentioned by at least 25% of the individuals interviewed (range 5 to 18 parent sources and 5 to 20 professional sources per theme). Seventeen themes were mentioned by over half of the participants, and 11 themes were mentioned by at least 75% of the participants.

Double coding. As is common in qualitative coding (Patton, 2002; Creswell, 2007), participants' responses to questions and general statements made throughout the interview, as well as the participants themselves, can often be 'double coded' into multiple thematic clusters and categories to represent more accurately the overall themes that emerged from the data. Thus, the number of participants (sources, *n*) endorsing each theme in a thematic cluster under any category would not always add up to the sum total of participants in either group. The same professional could be coded under multiple categories. For example, one professional stated,

But, whatever it is, we [professionals] know what the child's limitations and abilities of the child are. So, we will explain to them [parents] what it is and we will say what is the realistic goal that they can expect for him and can be trained to do. So, we will explain to the parents. Counseling plays a role there. We will say "this is what is required" and can be done here.

The above quote was coded under the theme "Primarily Professionals" in the 'Decision Making about Treatments' category. However, the same professional also stated,

Basically what we do is, like, any organization we go, it is a multidiscipline approach we follow. Like, many professionals will do the assessment, we get back on case conference, and then we will decide how we have to design a program with the child. And, then parent is also part of it. And, we develop an IEP. They are explained about what is decided for the child, and they also share their views, and their priorities are also considered.

Coders agreed that this statement reflected a more collaborative approach to decision-making about treatments, and thus the same professional was also coded under the "Primarily collaborative" theme in the decision-making category. Thus, it is important to note that the sources indicated in each table (*n*) reflect the number of statements that fit a particular theme

rather than the number of participants.

Table 1 presents all the categories and respective cluster of themes that emerged from the 19 parent interviews, number of parent statements fitting each theme, and the reference numbers or frequency of statements for each theme; Table 2 presents similar information for the professional categories and their respective cluster of themes. Although the reference numbers (*f*) represent text segments of varying length per reference, ranging from a few words or clauses to full paragraphs, these numbers provide a useful supplement to the number of interviews coded per theme in evaluating not only the saturation of content across participants, but also the density or frequency of discussion of content within themes.

Table 1.

Themes, Source Statements, and Number of References for Parent Codes (N=19)

No.	Theme Name	<i>n</i>	<i>f</i>
1	BELIEFS ABOUT CAUSES		
	Don't know or Unsure	18	35
	Religious and Spiritual Explanations	8	15
	Issues related to pregnancy and maternal health	6	15
	Genetics, Environmental Pollutants, Vaccines	5	8
	Disruption in traditional family structure**	3	7
2	DECISION-MAKING ABOUT TREATMENTS		
	Primarily collaborative process	11	23
	Primarily parents	10	22
	Primarily professionals	9	16
3	IMPLEMENTATION OF TREATMENTS		
	Primarily collaborative process	14	24
	Primarily Professionals	7	12
4	SATISFACTION WITH TREATMENTS AND SERVICES		
	Satisfied	15	32
	Ambivalent or Mixed feelings**	3	3
5	EXPECTATIONS FOR CHILD'S FUTURE		
	Independent living as an adult	16	25
	Hope for cure and normalcy	10	35
	Improvement in communication and speech	6	8
	Future is unclear and worrisome	5	7
	Hope for improvements**	3	4

Table 1 (continued)

6	PARENT-PROFESSIONAL RELATIONSHIPS		
	Positive, Collaborative, Trusting	18	68
	Need for better communication	5	6
	Paternalistic, Negative, Unreceptive to parental concerns**	3	11
7	AUTISM IN INDIA		
	Need for more awareness, acceptance, and mainstreaming	17	60
	Problems with resources, expenses, and accessibility	17	72
	Society is rejecting and critical	16	49
	Improvement in awareness, acceptance, and resources	8	14
	Society is supportive and accepting	7	11

** Findings not treated as a theme since there were less than 25% ($n=5$) of statements that fit this theme.

Note: n = number source statements that fit this theme; f = frequency of reference.

Table 2.

Themes, Source Statements, and Number of References for Professional Codes (N=21)

No	Theme Name	<i>n</i>	<i>f</i>
1	BELIEFS ABOUT CAUSES		
	Organic, Environmental, Combination Organic & Environmental	12	29
	<i>Purely Organic (Genetics, Biological, Neurological)</i>	8	18
	<i>Combination of Organic & Environmental (toxins, vaccines etc.)</i>	4	11
	Don't know or Unsure	7	8
	Parental/Familial, Combination of Organic & Parental/Familial	7	25
	<i>Purely Parental or Familial (blaming mothers, familial fighting)</i>	3	5
	<i>Combination of Organic (genetics/biological) & Parental/familial</i>	4	20
2	REPORT OF FAMILY BELIEFS ABOUT CAUSES		
	Don't know or Unsure	12	20
	Religious and spiritual explanations	8	12
	Genetics	8	10
	Issues related to pregnancy and maternal mental and physical health	6	7
	Parental self-blame, Disruption in traditional family structure	8	9
	Environmental Toxins, Vaccines**	4	4
3	DECISION-MAKING ABOUT TREATMENTS		
	Primarily collaborative process	14	28
	Primarily professionals	14	31
	Primarily parents	7	10
4	IMPLEMENTATION OF TREATMENTS		
	Primarily collaborative process	17	29
	Primarily Professionals	5	5
	Primarily parents**	3	4
5	REPORT OF FAMILY EXPECTATIONS FOR FUTURE		
	Hope for normalcy, cure, and academic mainstreaming	12	45
6	VIEWS ABOUT FAMILIES		

Table 2 (continued)

	Parents are unaware, uninformed, and gullible	13	26
	Empathetic and understanding of parental stress	12	22
	Issues related to income, education, and social class	12	38
	Parents are well-educated and well-informed	7	7
7	PARENT-PROFESSIONAL RELATIONSHIPS		
	Directive, Professional-driven	15	29
	Positive, Collaborative, Trusting	13	57
	Negative, Untrusting, Challenging	12	30
	Ambivalent or Mixed feelings	9	12
	Need for better communication	7	9
8	AUTISM IN INDIA		
	Problems with resources, expenses, and accessibility	20	62
	Need for more awareness, acceptance, and mainstreaming	16	35
	Improvement in awareness, acceptance, and resources	14	31
	Society and extended family can be rejecting and unsupportive	12	27
	Society is supportive, accepting, and nurturing	11	17

** Findings not treated as a theme since there were less than 25% (n=5) of statements that fit this theme.

Note: *n* = number source statements that fit this theme; *f* = frequency of reference.

Organization of Findings. The following sections summarize the content of coding within each theme, including presentation of definitions and exemplar quotations. First, in order to ‘introduce’ and ‘personalize’ the participants and enable more contextual understanding of the emergent themes, a summary of the investigators’ impressions of the participants in terms of their general characteristics and the overall tone of the interviews, as gathered from coding and analysis of the field notes and interview notes, are presented with relevant exemplar statements. Second, findings are organized by the main categories and then by parent and professional thematic clusters under each category. Categories and themes are presented within the Bronfenbrenner (1994) framework utilized in this study; organization of findings progresses from themes relating to individual experience of parents and professionals and their beliefs and practices regarding autism spectrum disorders at the micro- and meso-systemic levels to themes related to their overall perceptions of autism spectrum disorders in the cultural context at the macro-systemic level.

Participants: Overall Characteristics and Tones

Parents. Table 3 presents the demographic information and tone of interview as gathered from interviewer notes and overall impressions for each parent participant. In terms of the overall tones of the interviews, two primary themes emerged: (a) positive, hopeful, and relaxed, and (b) sad, hopeless, and overwhelmed. Parent participants in Table 3 have been organized based on their overall tones (i.e., positive or sad), rather than by their child's school setting or their assigned ID numbers.

Table 3.

Parent Characteristics Gathered from Summary and Memo Notes (N=19)

No.	M/F Age	M/F Education	M/F Occupation	Years s/ Child dx	Personality, Tone of Interview Pulled from Interview Notes
1	35/40	Bachelors/ Masters	STAH/ Managerial	9	Positive & relaxed; grateful for family support; pragmatic; complete acceptance of child's condition; realistic goals & expectations.
2	35/ No Info.	Masters/ No Info.	Special Ed teacher/ No Info.	7	Positive & relaxed; lots of support from extended family (lives with her parents); unsure about child's future but not anxious about it; grateful to God & supportive family; very thoughtful, & pragmatic in outlook.
3	38/42	Masters/ Masters	STAH/ Managerial	9.5	Positive & relaxed; great attitude toward life & child's disability despite challenges in past; open & honest; sometimes embarrassed to take child out in public but does it anyway; grateful for lots of social & financial resources.
4	32/34	Bachelors/ Masters	STAH/ Software Consulting	2.5	Positive & relaxed; forgiving & tolerant of society's criticism (<i>they are not aware</i>); grateful for good physical health & family support.
5	35/36	Masters/ Bachelors	STAH/ IT support	3	Positive & relaxed; secure; lots of financial, emotional & family support; calm & accepting; not rattled, in denial or defensive; worried about realistic things in the future (<i>who will take care after we are gone</i>); planful about future.
6	36/40	Masters/ Masters	STAH/ Managerial	3.5	Positive & relaxed; great attitude (<i>focus on strengths, not limitations</i>); supportive family & husband; positive, forgiving view of society (<i>they don't know about autism</i>); some realistic concerns about child's future but planful about it.
7	43/44	Masters/ Masters	Volunteer/ Consulting	5	Mostly positive but somewhat defensive in some places; expects full cure; strongly spiritual; very grateful for support from extended family; advocates for joint family system; especially defensive when talking about society's (negative) reaction to their family.
8	34/33	M/Phil/ Bachelors	STAH/ Engineer	4	Positive & relaxed; has been through a difficult journey to get to her current place of acceptance;

Table 3 (continued)

					good social support from family; good SES & resources; proactive; realistic expectations.
9	37/42	Masters/ Masters	Volunteer/ Software Engineer	5.5	Positive & relaxed; hopeful about future; no expectations for a cure; no trust in physicians; positive attitude toward society; reinforced everyday by child's improvements.
10	36/40	6 th grade/ HS drop- out	STAH/ Temporary job	10.5	Depressed & overwhelmed; low income; no family support; very difficult life; critical neighbors & extended family; access to services has been a life-long issue; family is socially isolated; marital disputes; hopeless, depressed & overwhelmed throughout interview (<i>I wish I could get rid of my son & die myself</i>).
11	25/30	HS drop- out/ HS drop-out	STAH/ Odd jobs	2	Depressed & overwhelmed; very unhappy; thankful that child is not worse off; low income; rejection & criticism from society (<i>they treat us like untouchables</i>); expects full cure for child; very socially isolated; cries a lot during interview.
12	30/38	Masters/ Bachelors	STAH/ Consulting	3.3	Depressed & overwhelmed; always worried, no happiness; spiritual & traditional beliefs; expects full recovery; society has been rejecting & critical; no support to take care of herself; sometimes husband blames her for child's problems.
13	32/39	Masters/ Masters	STAH/ Banking	4.5	Overwhelmed & defensive about child; upset that son is in special school; wants son to become <i>normal</i> ; strong spiritual beliefs; earlier had depression & anxiety but better now; hopeful about future; seems to view son's autism & her own past depression as personal failures; charged-up.
14	32/37	Bachelors/ Masters	STAH/ Managerial	5	Depressed & overwhelmed; exhausted; hopeful about cure; guilt & worry about causing child's autism; grateful for support of her parents & brother; in-laws very critical.
15	37/42	Masters/ Masters	STAH/ Consulting	12	Depressed & overwhelmed; soft-spoken; long pauses before each response; giving the interview seems like a huge strain; heart-breaking interview (<i>I have given my life to this, but is it worth it?</i>).
16	29/35	Bachelors/ Masters	STAH/ Software Engineer	2.5	Depressed & overwhelmed; tries to maintain a light vein during interview; jokes & laughs a lot but often ironic & mirthless; lots of life stressors (no social support, no extended family help, living away from husband); life revolves around child & child's schedules & needs; thankful that son is not more severely impaired; mainly overwhelmed but makes every effort to make light of it.
17	37/39	HS/ HS drop-out	STAH/ Low level laborer	1	Depressed & overwhelmed; guilt & worry about causing child's autism; strong spiritual beliefs & practices; grateful for supportive family & neighbors; stress related to separation from husband who lives in abroad.
18	37/40	Masters/ Masters	Volunteer / Managerial	8.5	Depressed & overwhelmed; not much social support, in-laws critical but parents supportive; society very negative; lots of sad, ironic laughter throughout interview; <i>autism is my life</i> ; no social life; grateful for support from God; frustrated.

Table 3 (continued)

19	27/34	No schooling/ HS drop-out	STAH/ Odd jobs	4	Depressed & overwhelmed; intense interview, heart-breaking; family's life is extremely difficult; very low income; moved from different city, don't speak language, don't read, moved away from supportive extended family; forgiving of society's attitude (<i>they are not aware</i>); whole life revolves around caring for twins with autism & making ends meet.
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Note: STAH = stay at home mother; M = Mother, F = Father, HS = High School.

The two primary themes were split fairly evenly across the interviews. Parents in both groups were influenced in their outlook and overall tone about their child's autism to a large extent by their personal level of acceptance of the child's disability and the level of acceptance from their extended family members, amount of support received from extended family, and the presence of additional life stressors; in general, the family's socio-economic status or the length of time that had elapsed since their child's diagnosis did not appear to have as notable an influence.

Positive, Hopeful, and Relaxed (n=9). In general, parents in this group were relaxed in tone and positive and pragmatic in their outlook to life and their child's disability. For example, one mother noted, *we only think, okay for some reason she has gotten this, what can we do now to help her and make her better.... How can I interact, what therapies to give... that is all we focus on*. Even though these parents had gone through a difficult journey, they had come to terms with their child's autism and fully accepted their child's strengths and challenges. Another mother stated,

Initially, it affected us a lot. Because, we had, as parents, we had so much hope for him. We usually feel... at the birth of a child, we have so many dreams for them. But suddenly everything has collapsed. But, I got a lot of support from my husband. He used to say that he is going to grow up in a different way. So, now we don't feel negative about anything. We just treating everything normally... everything is fine... we take him everywhere, to our friends' house and all... and even here at school they have told us how to handle all this behaviors in a new place and all that... so that has been very helpful. So, we take him regularly to one of our very close friend's house... that is also a routine, and they know how to deal with him. So, that way we are teaching him how to be at anyone else's house. So, that way we feel very happy that we are teaching him all these things.

According to yet another mother,

And apart from that even as a relationship, even my husband and I went through a bad time, you know because it is so challenging, and you start resenting that the other person, just because he can go to work, you feel you know, because I have become just a caregiver, and that is not a very, you know, mentally not a very exciting thing to do, or to do or not something you really enjoy all the time. So if people say that they do, I'd be surprised. So, you're cleaning up or mopping up some soup or tea, because we have been through it so much. And I have resented it so much that, ok you [to husband] happily went to work and having friends and you know having office parties and all that, and here I am sitting at home and attending to all this. So I went through that phase also. And then we realized ok, one person has to have a career, if we have to do financially well, you know... those things ... they come slowly. It is not that I've been wise or whatever from the beginning, you go through, you go through the turbulences, and then you realize what your priorities are.

These mothers all had supportive extended families, good resources, and a positive outlook about the hand that they had been dealt in life. For example, one mother stated,

. . . In fact in a way I feel it's been good for our relationship. Otherwise both of us are extremely independent and extremely on our own kind of people. Now we are more like a team, and ... my husband was an only child so he had a completely different outlook in life, you know. So much better. See my husband is more positive than I am. So whatever positive energy I get, he's like ok, this is something we've got and we are not the only one, it can happen to anybody.

Another mother, speaking about the support she received from her extended family, stated, *thank God! Everyone in the family understands my position, but they are not able to help too much by staying close by. Whenever they come, they take care of him.*

In general, mothers in this group were hopeful and pragmatic, regardless of their child's level of impairment, and were not rattled by worries and concerns about their child's future.

Sad, Hopeless, and Overwhelmed (n=10). Many mothers in this group acknowledged feelings of guilt and self-blame for their child's autism or behavioral challenges. Some mothers expressed feelings of defeat and hopelessness (*I have given my whole life to this, but is it worth it?*) and a sense of constant worry and sadness (*autism is my life*). In addition to dealing with

demands and stressors of their child's disability, these mothers often experienced rejection and criticism from society (*they treat us like untouchables*) and/or their extended families (*my in-laws are very critical*); were blamed for their child's behaviors by family, neighbors and strangers; and, based on their SES, sometimes had difficulties with resources, expenses, and accessibility to services. For example, one mother from a very low income family with three children, including twin daughters with autism and other disabilities, had moved from a different city for her children's treatment. She did not speak the regional language, did not know to read, and was completely isolated from her family and friends in her hometown. Most mothers in this group were emotional, cried, and spoke in a tired and strained voice in their interviews, while others sounded defensive and charged-up as if to 'prove' something to the world.

Gratitude. A common theme that emerged across both groups was a sense of gratitude and thankfulness for a variety of things, especially for support from husbands, extended family members, and the society. Others were thankful that their child's autism was not more severe, and for the *support and blessings from God*. Many mothers who hailed from economically well-to-do families expressed gratitude for the resources that they had at their disposal, the availability of multiple options in terms of access to services, and for considerably less worry about their child's future. One mother summed up her experience with the following statement.

I have learnt a lot from him [child]. I am thankful to have him in my life. I have learnt what true happiness is, what small pleasures are and all that from him... so I am really thankful. And, to get along in life in a very positive way... especially from [name of school] I have learnt a lot. Since... when I enter the school, all the teachers smile and talk in a very friendly way... I didn't know they were parents of kids with autism. So, after coming to know about it, I thought, 'see they are smiling so much... why can't I be more positive like them?' So, in that way, I have learned a lot from the school. I should thank them for that!

Overall, regardless of the tone of the interview, all parents were willing, forthcoming, and open in their response to the interviewers and seemed to appreciate having someone to share

their experiences with, even if talking about their challenges and life circumstances was sometimes emotionally difficult.

Professionals. Table 4 presents the demographic information and tone of interview as gathered from interviewer notes and overall impressions for each professional participant, especially with regard to their attitude toward and views of families that they worked with. Three primary themes emerged in terms of tone: (a) respectful, sensitive, and positive regard; (b) mixed feelings and views about families; and (c) critical views of families. Professional participants in Table 4 have been organized based on their overall tones (i.e., positive, mixed, critical), rather than by their school or work setting, or their assigned ID numbers.

Table 4.

Professional Characteristics Gathered from Summary and Memo Notes (N=21)

No.	Age	Sex	Specialty	Personality, Tone of Interview Pulled from Interview Notes
1	56	F	Psychiatry	Positive & collaborative; scientific thinking about causes & evidence-based; reassuring & supportive with parents; thoughtful & considerate; simple, clear communication; high family focus- <i>treatments not only idealistic but should work for families</i> ; strong focus on empowering mothers; open-minded; focused on “big-picture.”
2	43	F	Special Education/ Psychology	Positive & collaborative; scientific thinking about causes; director of school; respectful, firm & clear about what is offered at school; strong focus on communication w/ parents; business-minded to some extent.
3	42	M	Social Work	Positive & collaborative; don’t know about causes; thoughtful & kind; strong focus on families (<i>they are the most important</i>); clearly talks about how a family’s belief in causes would influence their approaches to treatments.
4	28	M	Siddha Medicine & Surgery	Positive & collaborative; Co-director of school; scientific-minded about causes & treatments; broad-minded & open to exploring <i>whatever will work</i> for each child; thoughtful; child-focused; respectful of parents; families see him as very approachable & speak highly of him; devotes a lot of time and energy toward establishing alliance & trust w/ parents; very accepting of all people who come to his school.
5	29	M	Occupational Therapy	Positive & collaborative overall; scientific-minded about causes & evidence-based approach to treatments; s/times frustrated w/ parents for not following through w/ suggested treatments; mostly authoritarian but tries to be collaborative & open to approaches suggested by parents; makes an effort to educate & inform parents at all times; sympathetic to parents’ struggles & frustrations.
6	33	M	Occupational Therapy	Positive & collaborative; scientific thinking about causes; respectful & sensitive to parents; feels responsible for child’s treatment & progress; some frustration w/ parents who are not as involved in child’s treatment.
7	40	F	Special Education	Positive & collaborative; scientific thinking about causes; genuine affection for the children she works with; not very informed about autism, makes many

Table 4 (continued)

				inaccurate statements; true sense of empathy & respect for parents; open to other treatment approaches; strong focus on open, regular communication with parents; feels fully responsible for implementing treatments & enabling progress.
8	46	F	Special Education	Positive & collaborative; Co-director of school; scientific thinking about causes; honest & open; thoughtful & sensitive to parent needs; child-focused; strong focus on regular communication w/ parents; parents spoke very highly of her.
9	31	F	Rehabilitation Counseling	Positive & collaborative; scientific thinking about causes; heartwarming interview; genuine love for children; very respectful of parents; sensitive & diplomatic in approach to parents; sympathetic to parent struggles; strong parent- and child-focus.
10	33	M	Rehabilitation Specialist	Positive & collaborative; professional & sensitive; family & child-focused; thoughtful; scientific-minded but says <i>I don't think about what causes autism</i> ; "holistic" approach to treatments; has a vision for what needs to be done; warm, open, helpful; described working with families as <i>absolutely fantastic!</i>
11	35	F	Special Education	Positive & collaborative; co-director of school; scientific thinking about causes; strong focus on child & family; thoughtful, sensitive & grounded; also a parent of child with autism; clear communication; reassuring to parents & open to new ideas; evidence-based thinking to treatments; dedicated to the field; parents speak very highly of her.
12	27	F	Naturopathy/ Yogic Sciences	Ambivalent or Mixed feelings; Co-director of school; some scientific thinking about causes; vague & unclear responses; not well-informed about autism but growing awareness; little experience in the field; clearly deferential of other director who is senior in age and experience by one or two years; mixed views about families – s/times empathetic, s/times critical & authoritarian.
13	26	F	Psychology/ Special Education	Ambivalent or Mixed feelings; talks a LOT; confused about causes but states <i>maybe genetics</i> ; vague responses; very high energy, very charged-up tone; judgmental of everyone else & Indian society; idealistic, grand ideas; frustrated with & critical of system & govt.; makes broad, sweeping statements; angry that others don't see what she does in terms of needs in the field, especially the professionals; more sympathetic to parents' concerns.
14	32	F	Psychology/ Special Education	Ambivalent or Mixed feelings; scientific thinking about causes; very earnest; lots of hierarchical notions & wants to stay within established boundaries at school; concrete; parents seen as mostly uninformed & unaware about autism & s/times frustrated by this; tries to be collaborative & respectful, but more authoritarian in approach.
15	29	M	Psychology	Ambivalent or Mixed feelings; some sense of blame towards parents for child's autism; authoritarian but empathetic (<i>parents are the real victims</i>); acknowledges parents' guilt for child's condition; parents seen as uninformed & in need of education about autism; sympathetic to parent struggles, concerned for their mental health.
16	28	M	Special Education	Negative; authoritarian; 'professionals know best' attitude; believes genetics & sociocultural factors causes autism (<i>it occurs mainly in rich families</i>); appears harsh & insensitive toward parents & children; concrete in thinking & responses; disrespectful of lower income families.
17	44	M	Special Education	Negative; believes autism is parent's fault; odd & mistaken ideas about autism; parents seen as uninformed & in need of education; authoritarian; vague in responses about treatments & goals.
18	24	F	Occupational Therapy	Negative; genetics as cause; high focus on family's social class; critical of lower and middle SES; minimal effort to be collaborative, 'professionals know best' attitude; child-focused; critical of parents.
19	43	F	Pediatrics/ Developmental Pediatrics	Negative; blames parents for child's autism but acknowledges there may be a genetic precept; highly critical of parents; critical & insensitive; business-minded; no patience for parents <i>who ask too many questions</i> ; many mistaken beliefs & inaccurate assumptions about autism; authoritarian; vague & unspecific about treatments & goals; says more expensive therapy = better quality of care.

Table 4 (continued)

20	31	M	Speech Language Pathology	Negative; strong beliefs in cold parenting as cause; acknowledge parents' guilt but also doesn't allay it; authoritarian; ambivalence towards working with families; tries to be open & collaborative but mostly 'professionals know best' attitude.
21	36	F	Speech Language Pathology	Negative; strong beliefs in cold parenting as cause; odd interview; stiff & said little; acknowledged parents' guilt but also doesn't allay it; authoritarian; ambivalence towards working with families; clearly deferential of other SLP & clear hierarchical difference between them.

Note: M = male, F = female.

Sense of Positive Regard: “Families are the most important” (n=11). A majority of the professionals in the study expressed positive regard for the families with whom they worked, appeared respectful and thoughtful in their approach, and expressed empathy for the struggles and challenges faced by the families on a daily basis as a result of their child's autism. One professional noted, *nothing in this world can be achieved without families. So, for me, it is families yes definitely.* These professionals talked about the importance of collaborating with the parents, stated that they actively sought to engage parents in treatment or educate them about autism, and expressed concern for the parent's well-being. For example, one professional stated,

Also see other professionals. Because they feel that, okay, 'if I go and see that professional because I've heard from newspaper, heard from website, heard from TV that he is doing,' then they say 'why don't I go and try it.' When they ask me all these things, 'Shall I go to that place?' I say okay. 'See, I cannot decide whether you go to a place or not. Whatever you want to do, you are free to do. But remember only one thing'....that is what I tell the parents. 'Whatever everybody is doing is to help the child. Plus he's trying to help you also. Take their information. Wherever you go, take a book and note down the units. Try to apply. See the results. Share with me, or share with them. And if it's good, if it's really good, I myself will go and learn from them [other professionals]. I will try to inculcate in my settings, in my therapeutic intervention, so it will be a holistic approach.' Wherein I have taken all the approach and I am trying to provide the best care to the child. My job is he gets to at least to a level where he can be independent. He can be an earning member of the family. 'And you [parents] are free from the burden of, oh, what will happen to him after.'

Many of the professionals in this group were fundamentally directive in their approach and shared ideas that reflected an underlying assumption that professionals often knew better about the most appropriate treatments for the child; however, they reflected sensitivity and thoughtfulness in their approach to addressing the needs of the child and the families, and

actively sought engagement and trust from the parents. For example, one professional whose statements clearly reflected the idea that parents are unaware and uninformed about autism and needed education in the topic, also stated that *parents, especially mothers, are the most important*. He devoted time to empowering the mothers, and designed interventions based on what will work for both the family and the child. Another professional noted,

Because it's not just the child, the child only spends 3-5 hours with us, he goes back to an environment, and if the kind of education that we are offering is not supported... then.... See, say we had a child and we provided a lot of visual aids and everything, and everything's structured, and he comes from a one-room tenement where the family doesn't have time or resource to support this for him, then everything we teach here becomes redundant because he cannot translate it in his home environment. So we also look at that... what is it that a family can practically do to help him, and then try to customize, and then we do that. So there are a lot of considerations while involving a program for a child.

Mixed Tone and Views: “Some are okay, some are not” (n=4). Professionals in this group were mixed in their overall tone and their views about families. While sometimes they sounded empathetic and sensitive to parents concerns and worries, at other times they expressed frustrations with regard to working with parents. For example,

Again you know it's like easy... it's easy with some, you don't even have to you know waste your energy on them. You can just be like, please do it and that is it. You are sure to get a result out of them. There are some you go on and on and on and you still not get a result out of it. Majority of parents are fine these days because we have had our own group treatments and you know talks and we have had parents talk to each other. Like in the US you have a parent association in every place, here we have seen backfiring of parents association because (laughter) again you know, it's more of cribbing about a place than seeing the benefits of it. So that's something we've seen.

These professionals mentioned statements that reflected their views of parents as being uninformed and in need of education (*many parents are even unaware of even the concept of autism. At least 85% of parents are not aware of what autism is at all*), but acknowledged that *parents are the real victims here*. These three professionals (all from different sites) had more hierarchical notions about parent-professional relationships as well as professional relationships

within their respective settings, but stated that they made an effort to educate parents and involve them in decision-making and treatment implementation. For example,

When I keep giving them assignments, homework, of course they do follow it. Probably the people who doesn't follow are mostly illiterates or aged people. They have difficulty in following my instructions. Except for those people... they are also... doesn't mean that they don't want to follow my instructions, but rather they don't know how to follow my instructions. Only that category. So, otherwise we find the maximum cooperation from the parents.

These three professionals were often frustrated and charged-up that there were higher level 'system issues' (e.g., lack of infrastructure and resources) that impeded treatment delivery and communication between families and professionals and between professionals. For instance, one young special educator commenting about the larger 'systemic issues' in India in the field of special education noted,

[Awareness among] parents and professionals both are needed. Because in India, the pathetic part is, to be a special educator, you don't necessarily have to be someone who is well-read. You can be a twelfth grade Pass and do this course and call yourself a special educator not understanding the full concept of special education. See that's again... where do we have our flaws? These are our flaws. No necessary that we are well read about the matter. I know a lot of people who have done the same diploma course and got an RCI [Rehabilitation Council of India] certificate and say I don't know autism. What is autism? At the end of it, I don't know it. Because at that one year, whatever I had a rote memory of, I vomited it and got my results so that's it. So how much understanding takes place. How much do you really want to work. Because there are a lot of people who are not per se special educators who work beautifully with children. They have no professional qualification but they work well. So these are things we have to look into. Because training, what kind of training. In one year can you really call yourself a special educator? A one year diploma especially, can you call yourself a special educator? Do you have that much exposure? Are you individually able to... because you are entrusting a life onto your hand. Taking a life on in your hand. Can you make any progress with the child? If you can't make progress okay, but don't hurt the child. Are you capable of doing something?

Although this educator spoke in much detail about these issues, here and in other places during her interview, she often made broad generalized statements that reflected idealistic and sometimes inaccurate viewpoints about special education in India. In general, these three

professionals came across during the interviews as earnest, idealistic, and young, and mentioned many themes that reflected a mixture of positive and negative views about families that they worked with and the larger Indian culture.

Critical Views: “It is really challenging to work with families” (n=6). Professionals in this group made statements that reflected an underlying view of parents as being uninformed and in need of education about autism, as well as conveyed an overall critical view of parents. For example,

Many people, they are not aware about it. Generally many people, like, those who don't know about it and they ask so many questions, and they doesn't know that this is an incurable thing or something like that. And they always think that it might be a genetic or uh many people say like 1 ½ years he was normal, what happens...suddenly it happens... it is like that only.

The statements made by this group of professionals during the course of the interviews often reflected a ‘professionals-know-best’ attitude with families, and they often expressed frustration that parents did not follow their advice on treatments implicitly. For example, one professional responding to a question about how he solved any disagreements with families about treatments to use with the child stated,

I will make them to agree. If I am saying that your child is having this problem, if they are not agree that, then I will uh I will ask them to sit in front of me and show the activities of the child, and I will make them to agree. Because most of the things are behavior problems. So we will explain to the parents; if they not agree that my child is not autistic or something and we will explain them with demonstration, so they will understand and then they will agree.

Professionals in this group often made statements that sounded critical of parental concerns, and were, in general, harsh and insensitive in their overall assessment/views of families. For example, one professional stated, *I prefer the uneducated because they don't ask many questions and will do as I say; the mother will ask can I put my child in normal school, and I say right away, no, she is a chromosomal anomaly.*

Some professionals in the group often commented on the family's perceived 'social class.' For example, one professional stated: *it is really challenging to work with these lower class and middle class peoples; upper class people are okay.*

Many of the professionals in this group also endorsed a belief that the parents were in some way or the other responsible for their child's condition and response to treatment. For example, one professional noted,

... lacking in parental inputs. That is proper parental input. So... there are children who have been left out without appropriate care or who have been left alone for most of the time, who have been left out in front of the televisions or computers for long number of hours. There, slowly the children who have been with those electronic medias, you know, slowly deprive the human touch and the emotional learning.

Notably, these professionals also frequently made statements that reflected an overall sense of negative regard for the families, a high level of frustration in their work with families, and lesser interest in taking a collaborative approach. For example, one professional, who explicitly endorsed a belief in parents being responsible in one way or another for their child's autism stated, *these children are the neglected children who have the TV as babysitter.* She further acknowledged that she had *no patience* for parents who did not want to follow the treatments she prescribed without question, and described her experience of working with families as *highly challenging*.

Overall, similar to parent participants, regardless of their tone and attitude, all professionals were engaged in the interviews and eager to participate. They spoke freely and clearly about their experiences of working with children on the autism spectrum and their families in this southern Indian city.

Thematic Category: Beliefs about Causes.

Overview. We asked parents and professionals what they thought caused autism spectrum disorders. Participants' direct response to this question as well as other statements that they made throughout the interview that were reflective of their beliefs about what caused autism was coded under this category. Across parent and professional interviews, one theme that was mentioned by both groups was that they did *not know* or were *unsure* about what caused autism. Similarly, participants in both groups also mentioned beliefs that reflected sociocultural factors as a cause, such as disruption to the traditional Indian family structure or the "joint family" system. Other themes that emerged that were more exclusive to the two different groups included factors related to organic causes such as genetics, biological or neurological factors; environmental pollutants, toxins, and vaccines; a combination of organic and environmental factors; spiritual and religious explanations; issues related to pregnancy and maternal health; and blaming of parents, especially mothers. Parent and professional codes under each thematic cluster in this category are discussed below.

Parents. All but one of the parents mentioned statements that reflected their uncertainty or lack of knowledge about what caused their child's autism. Some parents specifically stated that they *don't know what the cause of autism is*, while other parents implied that they did not know the cause. For example, one mother stated,

See when I browse the net, I get either it is because of the over dosage of medicine of what the mom takes, the second one is depression in her life, or... some stupid reasons. But, as you say, nobody is able find out why exactly autism is happening. See only when people know why it is happening, it will be possible for them to find out any solution for it. You should know why it is happening then there will be a solution.

Other parents (n=8) gave spiritual or religious explanations for their child's autism. For example, one mother stated, *I don't feel it is karma but I feel it's God's, like God has to distribute all the children who . . . and thus he's given him to us so that we will take care of him.*

Another parent stated, *Yes, I definitely believe in karma and fate and all that. That definitely played a role in causing this.*

Some parents talked about difficulties they experienced during their pregnancy, labor, or delivery as possibly being a cause. In particular, mothers spoke about depression or stress during pregnancy and family conflicts with extended family members as having possibly played a serious role in their child's autism. For example, one mother stated, *I was a little depressed when I was carrying him. I had a little family problems. Probably that might be a cause. I'm not very sure. I still have that doubt.* Similarly, another mother stated,

If I had to guess... I don't know... after marriage, I didn't have a good relationship with my mother-in-law. After I became pregnant with him, I had lots of problems... my mother-in-law and I would fight a lot. So, I have a doubt that this might have happened because of that. I stayed within the four walls of my house throughout the course of my pregnancy.... I didn't go out anywhere. I don't think I was ever happy during that time. I was always crying and always thinking of some problem or the other that would have happened with my mother-in-law.

About a quarter of the parent participants ($n=5$) believed that genetics, environmental pollutants or vaccines may have been a cause in their child's autism, but they were uncertain and skeptical. For example, one parent stated, *maybe it is environmental causes... we used to live in [place], which was a polluted area... so that may be the cause... chances are there.* Another parent stated, *people say it is all still in research stage. They say genetics, but even that is not confirmed.*

A minority of parents ($n=3$) mentioned ideas that reflected a belief in disruption to the traditional Indian family structure (i.e., parents moving away from a "joint family" system to live as a nuclear family with their children), but this idea is not discussed here in more detail since the number of statements that fit under theme were less than 25%. Table 5 presents all parent statements regarding their beliefs about causes for their child's autism, statement sources (n) and

references (*f*) for each, and exemplar statements representative of each theme.

Table 5.

Parents' Beliefs about Causes

Theme Name	<i>n</i>	<i>f</i>	Exemplar Statements
Don't know or Unsure	18	35	<p><i>I have no idea about it. I am totally confused.</i></p> <p><i>I don't know what is the cause of autism.</i></p> <p><i>This is the first time my family has heard the word autism. They have never seen another child like this. We all lived in a joint family. All children were normal. This is the first we are seeing autism in our family. So, it is very new to us.</i></p>
Religious & Spiritual Explanations for ASD	8	15	<p><i>Ummm... well... I think it could be because of someone casting an evil eye on me or him. My sister-in-law doesn't have children... rather, she didn't have children for 5 years when I was pregnant. After I conceived, she stopped talking to me. She cried a lot. She did all that. So, she might have cast an evil eye.</i></p> <p><i>Ok, see, you know there's a karma theory, you've heard of karma? So karma theory says you get... you get what you deserve. So as a person you think, God, I've not done anything wrong to anybody, so what have I done to deserve this.</i></p>
Issues related to pregnancy & maternal mental & physical health	6	15	<p><i>He was post-term. I only got admitted in the hospital 10 days post my estimated due-date. And, once I got admitted, they tried for a vaginal delivery for 2 days. I wonder if during that wait time, there was any deficiency in the oxygen sent to his brain or something. That is what the doctors also told us.</i></p> <p><i>Everyone in my town says that my stress during pregnancy could have been the main cause. I was very happy during my second pregnancy and that child is fully normal. He talks well and everything. So, I still have that original doubt.</i></p>
Genetics, Environmental Pollutants, Vaccines	5	8	<p><i>I have a feeling you are probably predisposed towards it</i></p> <p><i>Same thing as we thought you know maybe due to vaccination but nothing else.</i></p> <p><i>I think maybe genetics.</i></p>
Disruption in traditional family structure (i.e., "joint family")**	3	7	<p><i>Maybe... he is so attached to people... we were in joint family.... Something... everybody was... it could be the reason... even now, he loves people... he cries if people go. So, that could be a reason... [that they moved away from a joint family system]</i></p> <p><i>I think it is because we moved to a new house that was very lonely for her. The first house we lived in, there were lots of other kids, it was in the midst of a whole lot of things, lots of social interactions. I think the shifting home was the biggest problem. [this family lived in a traditional set up before]</i></p>

** Findings not treated as a theme since there were less than 25% (*n*=5) of statements that fit this theme.

Note: *n* = number source statements that fit this theme; *f* = frequency of reference.

Professionals. Professional responses to beliefs about causes were grouped under three

broad thematic clusters, namely, (a) Organic, Environmental, or Combination of Organic and Environmental; (b) Don't know or Unsure; and (c) Parental/Familial, or Combination of Organic and Parental/Familial. About 60% of professionals ($n=12$) believed that autism was caused due to organic reasons such as genetic, biological, or neurological factors ($n=8$), or a combination of these organic and other environmental factors such as toxins, pollutants, or vaccines ($n=4$). For example, one professional who wanted to relieve parents of any self-blame for their child's autism stated: *But the first thing I make them [parents] understand is it is biological. Right. They are not responsible in any ways for this. The parents are not responsible for this.*

Another professional stated,

I mean that is you know, I mean genetic loads the gun, and environment triggers it. So there is genetic background for autism, but when the environment favors it, it will manifest.

A third of the professionals ($n=7$) stated they *did not know* or were *unsure* about the causes, although six out of these seven professionals also mentioned other themes such as *maybe genetics? I am not sure but they say it happens only in rich families, or, I don't know really... it probably is genetics with something else, I don't know* during the course of the interview.

A third of the professionals ($n=7$) believed that a child's autism was caused by *cold parenting* and *parental neglect* of the child's emotional and social needs, as well as departure from the traditional Indian family structure (i.e., joint families) and the resulting social isolation.

For example, one professional stated,

So, the cause we generally feel is one, there has been an enormous change to the lifestyle in [name of state]. All because of the IT boom, information technology boom... All the parents, both the parents, the husband and wife, are in to work... okay, leaving the kid with a maid. So, mostly all these kids are being brought up in their initial years, where the speech stimulation is very important, the child's overall development is not there. Where the child is being brought up by a maid or other caretakers or the grandpa or grannies. So the child actually longs for mother's affection and dad's affection. So we also agree with Leo Kanner's refrigerator parents, cold parents.

Another professional stated,

It is only the autistic features... that is because of excessive TV watching, lack of stimulation by the working parents... usually, here, the grandchildren are taken care of by the grandparents. And, unless we have a good family support and set-up, these kids are left in front of the TV, TV has become the baby sitter in most of the households. It is quite unfortunate. I feel that is one of the reasons; excessive TV watching.

In addition to attributing parental blame and considering cold parenting as possible causes, these professionals stated that they shared their concerns about “parental neglect” of the child with the families and recommended to the families that parents spend more time with their children. Table 6 presents all thematic clusters in this category.

Table 6.

Professionals’ Beliefs about Causes

Theme Name	n	f	Exemplar Statements
Organic (genetics, biological, neurological); Environmental (pollutants, toxins, vaccines); Organic + Environ.	12	29	<p><i>According to me it is the imbalance in the neuro-chemical changes in the brain, in the neuro-transmitters. Or biochemical changes in the brain.</i></p> <p><i>Lots of issues are there. Genetics, medications of improper medications, and, mainly it is genetics. Depends on the gene, some problems with genes. That is the main thing I think.</i></p> <p><i>Like it could be vaccines. It could be other chemical pollutants. Like you know food additives, colors, flavors, I mean all the environmental toxicities together I am talking about. Yeah, apart from that lifestyle changes, deviating away from the nature all those things add up to the environmental toxicities.</i></p> <p><i>I think it would be something genetic, heredity. And it could also be triggered off by certain environmental factors. Like they say the type of food we eat is having an adverse effect on people. The type of food, the chemicals and the preservatives and all. It’s not like the food our ancestors used to eat. That was very natural. Now we got a lot of chemicals, we actually eat a lot of chemicals along with our food unknowingly. So it may cause some change in the structure.</i></p>
Don’t know or Unsure	7	8	<p><i>And, so the assessment bit, I wouldn’t... like you say what causes autism, I myself would like to know what causes autism. Because I am not clear.</i></p> <p><i>Currently, to my knowledge, with whatever the documents/research says, it is unknown, still not explicitly identified. But, there are some research saying that it is born to well-educated, high socioeconomic status parents; some are saying it might be because of some genetic causes. . . you know there are like that. So, there are different causes they are narrating, but so far it is not specific what it is.</i></p>

Table 6 (continued)

		<i>Causes for autism.. Through literature and all these things, there is no any specific cause what they have mentioned.</i>
Parents/Family (blaming of mothers, socioeconomic related, disruption to joint family units); Organic + Parents/Family	7 25	<i>It's a social economic status. See, suppose five autistic cases are there, in five autistic children, three are well to do, well to do families. Like rich families. And another one is middle class and another one is poor family, so uh most of the autistic children coming from well to do families.</i> <i>Umm... nuclear families... like, more of withdrawing support from joint family, and living now in independent set-up, and umm... family has to manage everything on their own; there is a lot of stress for them, undergoing to accommodate different activities.</i> <i>Yeah... parents will mostly be working, mostly some working women...</i>

Note: *n* = number source statements that fit this theme; *f* = frequency of reference

Thematic Category: Professionals' Report of Family Beliefs.

In addition to being asked about their own beliefs about causes, professionals were asked about their impressions of families' beliefs about causes. Professional participants' direct response to this question as well as other statements that they made throughout the interview that were reflective of their impressions about families' beliefs about autism was coded under this category. In general, thematic clusters that emerged in this category were highly consistent with those that emerged in the parents' Beliefs about Causes category. Consistent with parent reports, more than half the professionals (*n*=12) reported that families that they worked with usually *did not know* or were *unsure* about the causes of autism. For example, one professional stated,

Uhh... many parents are even unaware of even the concept of autism. At least 85% of parents are not aware of what autism is at all. And, even if few parents are aware... I think maybe less than 1% who might be thinking about the causes.

Similar to parents, many professionals (*n*=8) reported that families often attributed spiritual or religious explanations for their child's autism (*they see like it is a curse given by God or something like that. That still prevails in India that is for sure*), while still others (*n*=8) believed that families endorsed organic factors such as genetics (*they usually portray it to heredity*). Over 25% of the professionals (*n*=8) reported that families and mothers accepted self-blame for their child's autism or believed it was a result of disruption in the traditional family

structure and the consequent social isolation. For example, one professional stated,

A lot of people have come and said that I was a working mother and my child kind of was by himself pretty much, watching a lot of TV... So a lot of people believe that period of isolation, maybe from when the child was about 9 months to 3 years...where they say he did not have sufficient interactions, stimulation... is what a lot of people come and ask.. could that be the cause? Am I responsible for it.

Table 7 represents the different thematic clusters under this category, with number of source statements and references for each, and exemplar statements representative of each theme.

Table 7.

Professionals' Report of Families' Beliefs about Causes

Theme Name	n	f	Exemplar Statements
Don't know or Unsure	12	20	<p><i>Many people, they are not aware about it. Generally many people, like, those who don't know about it and they ask so many questions, and they doesn't know that this is an incurable thing or something like that.</i></p> <p><i>Parents are still skeptical about it; they are not aware of it. About what has caused their child to be different from us. Because, it is invisible, right? So, they are unable to compare with any other children having this. Also, no two children are identical; so they are unable to see what it is.</i></p>
Religious and Spiritual Explanations	8	12	<p><i>Oh, yes yes yes! "This is due to my past sins, it is my karma." Karma is something that helps them to accept it. This is my "poorva janma' karma, th is my previous birth's karma... I have to go through it. If I escape, in the next birth also I will be suffering. So this is my karma." Once they feel this is my karma, they accept..</i></p> <p><i>Not from the educated group. But, yes from the low-income group. They may feel that maybe it's the will of the Almighty who has given this child to us. And we are trying our level best. Whatever facility we have, we will try to provide for this child.</i></p>
Genetics	8	10	<p><i>The family believes that it is uh kind of a delay speech or there kind of the problem in uhh the genetic problem or their family believes that their family itself is the causes. My, my... I talked only after 6 or 7 years, or I started to communicated delayed. It is the kind of their family line they said this is the cause.</i></p> <p><i>Many people, you know many people really think that it is some father's family or mother family that is the reason.</i></p>
Issues related to pregnancy and maternal health (mental & physical)	6	7	<p><i>So, according to their history, their natal history, their birth crying, heart patient, and mother have hypertension during the pregnancy time, during the pregnancy time mother develop hypertension, and if mother have fits [seizures] during the pregnancy.</i></p> <p><i>Some parents had complications at the delivery time, they had problems with asphyxia. Then some, they say it is due to epilepsy.</i></p>
Parental self-blame; Disruption in joint	8	9	<p><i>. . . Many of them of have said that probably it could be that they haven't exposed these children to the social environment... the nuclear family, you</i></p>

Table 7 (continued)

family structure			<i>know... it's just the mother, father and the child. So, the child is not exposed to other people.</i>
			<i>So it is.. you either see people who feel a little guilty about something that they have done, like we have had a couple parents who have said I did not want this child and I kind of wished at that point that I wasn't pregnant, and maybe that's why.</i>
Environmental toxins, vaccines**	4	4	<i>Many people really are convinced that vaccines are the cause and they say till 1 ½ years he was talking, after the speech started you know uh and regressed kind of thing, you know, that's what happened. Yeah, another thing is other chemical...in we are living near the chemical industries, other things and all, very rarely only they are they reporting.</i>

** Findings not treated as a theme since there were less than 25% ($n=5$) of statements that fit this theme.

Note: n = number source statements that fit this theme; f = frequency of reference.

Descriptive Category: Treatments and Services.

Overview. We asked parents what treatments and services their child with autism was currently receiving and professionals about what treatments and services they usually provided. However, since we did not observe any of the treatments being implemented with the children or gain more information about what those treatments specifically entailed, information gathered on this topic is presented in a descriptive manner rather than thematically.

Parents. In general, across the sample, parents said that their children received a combination of different therapies such as speech and language pathology, occupational therapy, special education, and special routines and practices across different settings such as school, home, and community. Given that parent participants were recruited from school-based setting, all parents ($n=19$) stated that their child with autism received most of the services provided by the schools that they were enrolled in, such as special education, speech and language therapy, occupational therapy, and participation in group activities and games. In addition, some parents reported that their child received community-based speech and occupational therapy in an outpatient setting. Other parents reported that their child received after-school “remedial” or tutoring in-home or in a community setting that focused mainly on academic skills.

Almost all the parents ($n=18$) reported that they implemented special morning, evening,

or weekend routines with their child (e.g., going to the beach to walk on the sand for sensory input), followed home programs prescribed by the schools, and/or implemented special diets for digestive, allergy, and weight-related issues. With regard to special diets, a few parents reported that they, currently or in the past, followed popular autism-specific diets such as Gluten Free Casein Free (GFCF) diets or providing supplements and vitamins. Most other parents reported that dietary modifications were more for the purposes of dietary restrictions of certain foods that their child was allergic to or were unhealthy in general (e.g., sodas), or due to the child's sensory-sensitivities or picky-eating.

Some parents ($n=8$) reported that they as parents followed specific spiritual practices for their child's recovery or well-being such as fasting, offering special prayers, or making a special offering to their family deities. More than half the parents ($n=13$) reported that in addition to school-based therapies and home programs, their children received traditional Indian treatments such as Ayurveda, Siddha, and Yoga to help with symptoms of autism such as behavioral challenges, sensory-based issues, and to *promote healing*.

Professionals. In response to a question about what treatments and practices they used most with children on the autism spectrum, a majority of the professionals ($n=16$) endorsed practices specific to their discipline in a school-based setting such as special education, behavior management, speech and language therapy, and occupational therapy. Professionals stated that treatment practices were often based on a combination of adapted strategies from Western approaches to intervention. These included services such as Applied Behavior Analysis, TEACCH, and other individualized educational interventions; speech and language based therapy that is usually focused on articulation and improving expressive and receptive communication using approaches such as Picture Exchange Communication; occupational

therapy services based in sensory integration approaches; and social skills building based in strategies such as Floortime and Relationship Development Intervention. In addition, children also participated in more informal group play and sports such as skating, and music, art, and dance.

About 50% of the professionals ($n=10$) stated that they or their schools also implemented traditional Indian practices such as yoga, Siddha, and Ayurveda as part of the child's treatment, and two professionals said that they recommended special diets and supplements to the families for their child's autism.

Goals of and Expectations from Treatments. One theme that emerged from the professional interviews when participants were describing treatments and services was their goals and expectations from these treatment approaches. The most common expectations from and goals of treatments implements included behavior management and control, increased adaptive living, increased ability for communicating wants and needs (verbally and through signs), independent living in the future, and improved functional academics. One professional, talking about the importance of behavioral management and control, stated,

That's our, that's our goal, that's primarily what we work with a lot of them. Doesn't matter if you don't do an iota of work, but if you can manage yourself, behave appropriately, and you know and get on with your life. There might be someone who is willing to take care of you. A lot of maladaptive behavior, who resort of a lot aggressive behavior, then even with any amount of money, it is going to be hard.

With regard to independent living, one professional stated,

Our idea is to make him stand on their own legs. I am not for academic skills; I am for life-help skills. I tell them very clearly. I tell them, this is not book knowledge, it is life skills. Your child should be able to stand on his own legs, let us start working for it.

A few professionals talked about academic mainstreaming and inclusion as the major goal of treatment. For example, one physician stated,

As I've told you, the ones who believe in my therapies and the diet and everything, I have a significant number who are going to normal school. They are given certification saying that all the autistic features improving, child can attend normal school. I tell them [parents] also, ultimately we all want our children to go to school, to be more independent, to take care of themselves, and to have a decent education.

Notably, with the exception of three professionals, nobody talked about improving pragmatic language, play skills, or maintaining friendships and social relationships as a goal for treatment.

Thematic Category: Decision-Making about Treatments.

Overview. We asked the participants what their role was in selecting treatments for children with autism, and the role that the other group (i.e., parents or professionals) played in the process. In addition to participants' direct response to this question, other statements that they made throughout the interview that were reflective of their role in the treatment-selection process were coded here. Across parent and professional interviews, the three main themes that emerged in this category were *Primarily Collaborative*, *Primarily Parents and Family*, and *Primarily Professionals*. The word 'primarily' is key in these codes, since most participants often endorsed multiple views and sometimes made seemingly-contradictory statements; overall, the decision-making process as described by both parents and professionals involved a combination of approaches that are described in more detail below.

Primarily Collaborative. Statements made by parents and professionals that were considered an appropriate fit for this theme included direct or implied statements that referred to both the parents (or families) and the professionals offering suggestions for treatments, having a conversation about what treatments to use before implementation, and actively reaching consensus, regardless of who first proposed the treatment. As long as the professional made an effort to explain the rationale behind treatment decisions and engaged parents in conversation

about what treatments to use with the child, the process was considered to be collaborative in nature, even if the professionals made the initial decision about what treatments to use with the child.

Primarily Professionals. This theme included direct or implied statements from parents and professionals about professionals being solely responsible for deciding treatments for children with autism or having the final word in the decision making process. Professional statements that referred to their views of parents as uninformed and unaware of autism (thereby needing education about what treatments would be most appropriate), and/or explicitly acknowledging that parents had little to no role in this process were coded under this theme. In addition, parent statements that conveyed a sense of helplessness about not knowing what to do for their child, a lack of choice once they entered certain schools, or in contrast, a sense of complete trust in the professional to do the best for their child were coded here.

Primarily Parents. This theme included parent and professional statements that implied or referred explicitly to parents having the final word in the decision-making process or to professionals having little to no role. Responses where parents made no mention of professionals with regard to decision-making about treatments were also coded here.

Parents. Most parent statements ($n=11$) with regard to the decision-making process regarding what treatments to use or what services to seek for their child indicated a relationship that was primarily collaborative in nature with the professionals. One parent stated,

Yes, in the school, where the teachers will come in contact with us. We will express our views, they will also tell what improvement they have found in our son and this is how we are able to manage and we are able to make decisions. And we can tell our suggestions, this is where we need our son to improve. And this where we have to help them out and all those stuffs like that.

Another parent stated,

Well, we will see if it is useful to her. That is the most important thing. If it is good for her, we will do it. We consult as a team and do it, that is my husband and I. We will also work together with the school to figure out what is best for the child. We listen to all the suggestions by the school, but we take the final decision.

Almost an equal number of parents also mentioned statements that indicated that decisions about treatments were made primarily by the family with input from friends and other parents of children with ASDs ($n=10$). For example, one parent stated, *it's like our family decides, it's me, my husband, and my father.* Another parent reported,

Professionals actually.... they don't have a big role in deciding what he wants as such....they just help him to do whatever therapies work. Other than that, they don't guide us about what to do.

Less than 50% of the parents' statements ($n=9$) acknowledged that it was only the professionals who made all the decisions. For example, one mother stated,

I have to consult with Sir about it and only then decide. Each child is different, right? If she needs it, we will give it. We should decide soon. Sir even said she doesn't need speech therapy... he said she only needs communication therapy, since she naturally has speech, but she only needs to improve in her communication. He said it is up to us [school and home] to bring out that speech that she has. So, he asked us to cooperate.

Another mother stated,

If they tell us that we have to do it, we have to do it. There is no choice. You never know. Maybe this time there will be some improvement.

Table 8 presents the theme clusters about the process of decision making about treatments as reported by parents, statement sources and references for each, and exemplar statements describing each theme.

Table 8.

Parent Report: Decision-Making about Treatments.

Theme Name	<i>n</i>	<i>f</i>	Exemplar Statements
Primarily Collaborative Process	11	23	<i>Yes, whatever I have observed, I make it a point to note down in case I forget. And, I tell them, every small improvement or suggestion, I make it a point to tell them. So then whenever I meet them, I get their feedback.</i>

Table 8 (continued)

			<i>It's a teamwork. If the school suggests something, if the therapists suggest something, then we will discuss this. We will discuss together, they'll discuss to me, and I'll discuss to my parents. It's like teamwork, through family and through her therapists and her school teachers.</i>
			<i>It is a team work. At the end of the day, there should be some improvement for all the kids. That is what each and every parent is expecting.</i>
Primarily Parents (including, consultation with extended family members and other parents of children with ASD)	10	22	<i>Ah yes and again we got the guidance from many of the parents. They taught us this therapy was good for my child, so why don't you try that... that is how we got information about treating autism. [About this school] also we got the information from a parent.... And, yes, we make the decision as a family.</i> <i>uh yes my husband and myself and my parents. They [her parents] are nearby so they are involved.</i> <i>My decision mainly.</i>
Primarily Professionals	9	16	<i>Both of us consult Sir for everything. Whatever Sir says, we will follow. He had asked to come to talk about skating, but we haven't had a chance to do that yet, to meet with him. We need to meet him and ask him what to do next.</i> <i>They are educated in this area and have experience with so many different kids. So, they will definitely be doing things that are best for my child. So, I trust them.</i> <i>No, I just do what the Sirs here tell me to do. What else can I do?</i>

Note: *n* = number source statements that fit this theme; *f* = frequency of reference.

Professionals. About 40% of the professional statements (*n*=7) indicated that parents had the primary role in selecting treatments. According to these professionals,

Yeah, yeah most of the time is it the parent. As an educator, as a doctor, I can say a lot of.. I mean when parents go to them, you know, there is a limitation. We can only tell them. Because today if I tell them ok don't do it it's upon them. If I force it a little they go to change the therapist. Today I am a special educator, tomorrow someone else becomes, because I am not pleasing the parent. You get it? So when I am not pleasing the parent, why would she want to be with me?

A majority of the professionals, however, mentioned statements that referred to decision-making about treatments as bring primarily the professionals' role (*n*=14) or primarily a collaborative process (*n*=14). Professionals who mentioned statements that referred to professionals having a primary role sometimes believed that it was because the parents were uninformed about autism or because parents expected them to make the decisions. For example, one professional stated,

But, whatever it is, we [professionals] know what the child's limitations and abilities of the child are. So, we will explain to them what it is and we will say what is the realistic goal that they can expect for him and can be trained to do. So, we will explain to the parents. Counseling plays a role there. We will say "this is what is required" and can be done here.

Another professional stated,

They [parents]... when they come to us, they are not in a position to decide what to do. After 2-3 sessions only they will understand what to do. They will follow whatever, you know, the guide gives to the parents, to some extent they understand.

On the other hand, professionals who stated that treatment selection was a more collaborative process believed that parents were informed about their child's condition, were the best judges of the family's and child's priorities, and actively sought and encouraged parent engagement in the process. For example, one professional stated,

It should be feasible and possible for them. What is ideal is different, what is practical, what is possible. Maybe practical but it should be possible. The mother may be carrying one infant. So, depending on all these things, I have to tell them what to do.. this is ideal, this is possible. Okay, at least I will start doing something....

Another professional stated,

Even though it is a school setting, I see to that it is more of a family centered approach. We take a family centered approach and I try my best to incorporate the family members, the caregivers, the primary caregivers and the teachers as well.

See Table 9 for theme clusters about the process of decision making about treatments as reported by professionals, sources and references for each, and exemplar statements describing each theme.

Table 9.

Professional Report: Decision-Making about Treatments.

Theme Name	<i>n</i>	<i>f</i>	Exemplar Statements
Primarily Collaborative Process	14	28	<i>This is again the teacher, the consultation with other professionals, and the parents also part in it. So, all these people decide what treatments to use with the child.</i>
			<i>We don't say don't give milk and we don't say give milk. We say ok these</i>

Table 9 (continued)

			<p><i>are all the facts about it and these are all the literature and scientific studies we have in our hand, and you can you know choose it.</i></p> <p><i>Basically what we do is, like, any organization we go it is a multidiscipline approach we follow. Like, many professionals will do the assessment, we get back on case conference, and then we will decide how we have to design a program with the child. And, then parent is also part of it. And, we develop an IEP. They are explained about what is decided for the child, and they also share their views, and their priorities are also considered.</i></p>
Primarily Professionals	14	31	<p><i>First, medical practitioner has to decide that the children's having features with autism. Then it has to come to the educators. Then educator will plan accordingly to the level of the child to (noise) developed their activities. So the doctor is uh the medical doctor is playing important role to the children's autism. So after diagnosing that they will send to the educators.</i></p> <p><i>Actually, I will guide the teacher. It depends on the condition of the child, and how they are going to interact with the child. You know, whether it is individual or group. Depends upon that. Then, I will guide the teachers accordingly about what approach is to be chosen. [this professional is the head of his department]</i></p> <p><i>Since we have done a course on it we have more knowledge on it.... [mumbling] Maybe we will be able to help them focus what they have to do. So, what we do is, we will plan out a goal for the child and we implement, and... along with them [parents] only, and we will show them the success on that, and we will also help them to understand that what they have expected is not more useful for the child.</i></p>
Primarily Parents	7	10	<p><i>No. It is purely the parent's interest.</i></p> <p><i>Some of them prefer Ayurveda. It depends on you know, maybe their family background. And their own experience, you know, with other forms of the system. So they choose...and even on the condition of the child, maybe the child was very hyper active, they may want him to have occupational therapy. Whereas a child who is calm and who is able to attend to some work, they may like to put him more in to academics and more in to... and, with an older child, they are very interested in vocational training.</i></p> <p><i>It's the parent's discretion.</i></p>

Note: *n* = number source statements that fit this theme; *f* = frequency of reference.

Thematic Category: Implementation of Treatment

Overview. We asked parents and professionals about their role in treatment implementation (e.g., who does the therapy, how much are families involved in their child's treatments, do professionals give parents home programs to follow with their child etc.). Similar to other codes, in addition to participants' direct response to this question, other statements that they made throughout their interview that were reflective of their role in the treatment implementation process was coded here. Parents and professionals both agreed that the process

of treatment implementation with the children was primarily collaborative. Since almost all participants were recruited from school-based settings, the general model of treatment delivery was that professionals took the lead in delivering services to the children at school and provided parents with home-based programs to practice with their children outside of the school setting. Further, almost all the schools involved the parents actively in the treatment process. Two of the five schools highly encouraged parents to be part of the everyday routine of the schools, helping them observe and learn as well as teaching them how to implement the different strategies in a hands-on manner with their own children and other students in the school. The other schools regularly communicated with parents about their child's progress and teaching strategies and invited parents to observe and learn *in-vivo* as often as possible.

Many participants, especially parents, who mentioned that treatments were mainly implemented by the professionals referred most often to discipline-specific strategies such as in occupational or speech therapy, or because families and parents were too overwhelmed by other life demands to be able to follow-up with their child's treatments outside of the school setting. No parents reported that they believed that it was solely their responsibility to implement treatments with their child; among the three professionals who stated that it was mainly the parent's role, two were physicians who primarily consulted with the parents about treatment strategies (i.e., they did not directly implement treatments with the child), and one was a school professional who stated that parents who came from out-of-state were taught to implement the recommended strategies on their own with their child back in their home town.

Parents. A majority of the parents believed that the process of treatment implementation was collaborative ($n=14$). These parents specifically talked about professionals taking the lead to implement treatments in the school setting, and then working together with the parents to help

them learn how to follow-up on those strategies using home programs. For example, one parent stated,

Yes, they invite us for observation classes. They will show us exactly what they are doing with her. Like, clay play, mirror play etc. So, I have attended those observation classes. And, then I try them at home. Even clay activities to improve her finger flexibility they do here, and I follow at home at least for 10 minutes every day without fail.

Another parent stated *it is the professionals' responsibility at school. Then they will give us suggestions for how to do it at home, and we follow it.* One mother spoke about how she was involved every day in her son's treatment at school,

The professionals do it here, and then teach us, too. So, even in the school, we are involved in the treatment process. I come here with him every day and stay the whole time. The teachers cannot manage everything on their own. Because each class has about 7 students, so, all the parents will be there, and we will be the main people implementing the treatments with our children.

Some parents ($n=7$) also mentioned statements which indicated that it was mainly the professionals' job to implement treatments with their children. These parents believed that the professionals were more knowledgeable and had more expertise in their discipline-specific strategies. For example, one mother stated,

OT, we cannot really do like how professionals do it here. They have specific equipment and things that we cannot get outside. We can't do it as well as them, I believe. If everyone is able to do it, what is the use of those professionals going through all that training? We can only get an idea about what is happening, we can never implement it to their level.

Another mother stated,

No, they do it all. For example, he learns yoga here from teachers. But, I cannot do that with him at home, right? The professionals are educated in that subject, so only they can do it properly. I cannot do it the same way.

Some mothers in this group stated that they had other competing life demands that left them with little choice to work with their child after school. For example, one mother of twin daughters with autism shared,

We come here at 9 AM, and then I sit here until 1 PM. Then, after going home, I have to attend to chores at home and then go to pick up my youngest daughter. So, I don't have time at home to work with them.

Other mothers reported that the professionals at school usually took care of all the treatment implementation and did not give many home programs for the parents to follow at home. For example, as per one mother,

Here they haven't yet given me home programs. They have just told us to draw with crayons at home with child. They said they will give us home programs after a month. So, maybe I will get it next month.

Table 10 presents theme clusters about the process of implementation of treatments as reported by parents, statement sources and references for each, and exemplar statements describing each theme.

Table 10.

Parent Report: Implementation of Treatments

Theme Name	<i>n</i>	<i>f</i>	Exemplar Statements
Primarily Collaborative Process	14	24	<p><i>And then after coming to [school], they said that just doing puzzles and sorting is not enough for him, you need to communicate with him. They guided us in a very good way and they told us, he has to communicate. So, after I had put him in a special school, I felt that there are other ways to make him communicate. So I used to follow whatever [this school] told us and trained us on. Like the sign language and all that... we used to fully follow it correctly at home.</i></p> <p><i>They keep us [informed], we get feedback what has happened, what assignments is for doing at home, they take the feedback from us on what he is doing at home and all that, and based on that they give OT, and they help in academics also. Like training the child to write.</i></p> <p><i>Yes, they tell us all that very clearly and also teach us how to do it correctly at home</i></p>
Primarily Professionals	7	12	<p><i>It is the professionals' responsibility at school. We don't interfere much with that, especially OT.</i></p> <p><i>I go home actually, I don't stay with him.</i></p> <p><i>I don't have any help. I stay alone with them, so I don't have time.</i></p> <p><i>So far, I haven't observed any live therapy sessions anywhere for my child. They will take her separately and later report to me what they did in session.</i></p>

Note: *n* = number source statements that fit this theme; *f* = frequency of reference.

Professionals. A majority of professionals ($n=17$) mentioned that treatment-implementation was primarily a collaborative process. These professionals stressed the importance of consistency across settings for the child and the important role that parents played in their child's life in general and in ensuring consistency and follow-up. For example, one professional stated,

It's a two way process. Parents have to be involved but most of them we don't get because again it's like, I've sent the child to you, so it's your responsibility. The end result should be provided by you. But it's not always that...because whatever the child learns, the child has to generalize it. Right? If I am going to work with the child to indicate toilet and water, I cannot only use it at home. I have to start making sure the child starts indicating in other places. So where does the child spend most of its time? At home. And with parents, and you know whoever his immediate family is. So whenever he goes out, who does he do it more with? Them. Because you know ... vacation ... whatever... the most hours of time spent is with the parent. So if the parent doesn't work, the child doesn't benefit, so it's a two way process. We try getting the parent in.

Another professional stated, *absolutely, absolutely, we try [to involve families] as much as possible.*

The child psychiatrist that we interviewed believed that parents, especially mothers, had to be empowered to feel confident about taking care of their child's needs. Speaking about the message that she provides families that come to her, she shared,

You go to the temple if you want, you pray. I am not preventing it. You do whatever you want but in addition, do what I'm saying. Early intervention is the 'mantra.' And, it should be done at the family level. Whoever is training you, your job is this. I know it is going to be very difficult but this is an investment you are making for the child's future. I make it very clear.

About 25% ($n=5$) of statements mentioned by some professionals indicated that they believed that the professionals were primarily responsible for implementation of treatments. One professional stated that although in a school-setting this process is usually more collaborative with more parental involvement, in private practice settings, professionals are expected to do more.

See, actually, the previous one was more of private organization where I worked. There, and in any private place, they expect more to be done by the professional. And, they pay for that. So, even parents expect us to do the maximum load. They will be there. They know what is happening with the child, but they will expect professionals to contribute more than parents.

Another professional in a school-based setting stated that parents *made them*

[professionals] *free* by entrusting their child's care completely to the professionals: *Yes, some parents are like that. They make us free... okay, he is in your hands now, you are free to do what you want.*

Only three professionals in the sample stated that it was the parents who primarily implemented treatments; since less than 25% of statements mentioned by these participants fit this theme, this is not considered a significant theme that emerged from the data. See Table 11 for theme clusters about the process of implementation of treatments as reported by professionals, sources and references for each, and exemplar statements.

Table 11.

Professional Report: Implementation of Treatments.

Theme Name	<i>n</i>	<i>f</i>	Exemplar Statements
Primarily Collaborative Process	17	29	<p><i>Families are not much involved in the classrooms but they are involved when they work individually on cases, usually, and they do help us, they participate in it very actively. Yes, definitely [give parents home program to practice with child].</i></p> <p><i>No, no... parents uh parents watching what we are doing with the child. And simultaneously the professionals are expected to train the parents also. So what should they do in the home. And what should they, should do and shouldn't do at home, and all these aspects they are simultaneously teaching the parents. So you can see that in our institute, all the children are coming with the parents or the caretaker. No child is coming alone except in the vocational department some adults are coming alone, but the children generally they are coming with the parents.</i></p> <p><i>Uh, to begin with there will be some little involvement, because we are actually developing the pairing with the child. Later we will be, you know, later in the sense, every 15 days, once in 15 days we will be calling the parent to come and watch. For example, if it was yoga, 15 days we will be having a parent observation form kind of. The parent will come and observe, ok this is what we are teaching the child and we are teaching this for this purpose. And if you do this, all these things can be accomplished. That's what we will say and parent, some parents do video-shoot it kind of</i></p>

Table 11 (continued)

			<i>thing and they have certain areas, like ok I mean, 'how is his alertness now, how is his attention now, how is his sleeping behavior now, how is his gut now.' And, you know that has to filled by the parent. So it does happen once in every fifteen days. Three months of yoga time goes, we will be comparing with the first 15 days with the 6th 15 day and we can... kind of thing.</i>
Primarily Professionals	5	5	<i>We start intervention. I have a group of people. I have a clinical psychologist, an occupational therapist, speech therapist... not in here, but attached to the hospital... SMF. We work as a team. [team of professionals]</i>
			<i>No, most part of the therapy would be done at the center. And, at home, it will be more of uhh... a small part of the work.</i>

Note: *n* = number source statements that fit this theme; *f* = frequency of reference.

Thematic Category: Satisfaction with Treatments and Services.

This category was exclusive to parent participants. We asked parents if they were happy with the treatments and services that their child currently received in their respective school placements. In addition to their response to this question, other statements that parents made throughout the interview that were reflective of their opinion about treatments and services were coded in this category. Across all parent interview, the one main theme that emerged in this category, which was endorsed by almost 80% of the parents (*n*=15), was that parents were *very satisfied* or *very happy* with the treatments and services that their child was currently receiving. Parents spoke about their satisfaction mainly in terms of improvements that they have seen in their child's behaviors and skills, and believed that the strategies and approaches to treatment followed by their child's school and the different professionals working with them was appropriate and effective. For example, one parent reported, *I think a lot of improvements have come. Basic discipline has come for my son, because that was really lagging before. I'm extremely happy ma'am.*

Another parent reported,

Now, after coming here, he goes and sits with other children... he has improved so much since he came here to this school. Before, he could orally recite from A to Z, but did not understand that this was A or this was B. He would repeat anything we teach him very accurately, like picture names or whatever is drawn on the board. But, he didn't

understand anything of what he was saying. After coming here, he is able to spell different words, like B-A-L-L. Now, he is much better than before.

Three parents endorsed mixed or ambivalent feelings about the treatments and services, and one parent had no opinion about treatments and services provided for their children. For example, one mother stated,

I have not yet seen any improvements, but they say it will take a couple of months. That is what they say at my house, too. And, that is what Sir [Director of school] said, too. That improvements can be seen in a couple of months only.

Since less than 25% of parent statements reflected more ambivalent or mixed feelings, this is not considered a separate theme in this category.

Thematic Category: Parents' Expectations for the Child's Future.

This category was also exclusive to parents, and they were asked about what expectations they had for their child's future. Almost 85% of the parents ($n=16$) stated that they hoped for their child to be able to live independently as an adult. One mother stated,

Just that... I want him to be independent, not dependent on anybody. He can manage on his own. Just I want to keep our hope that something he has to manage... not that he has to become a doctor or anything like that.... He should know how to lead his life. Because none can support anybody in this world... even a normal person cannot be supported in our needs. So, I want him to know how to handle his life, that is it.

Another mother stated,

Just that they should at least be able to take care of their own needs. I want them to be well. I don't care if they don't study well or if they don't have high education, because I know their brain is slow. But, I at least want them to take care of their own needs.

In general, parents hoping for their child's independent living in the future specified that they did not expect high academic achievement. Rather, what they hoped for was improvement in basic adaptive skills such as managing their own personal hygiene, understanding simple monetary transactions, or cooking a simple meal. For example, one mother stated,

I expect her to be independent. She should be able to manage her own self-care, her daily living activities, at least the basic things, she should be able to manage independently...

self-help skills like toileting, feeding, dressing, drinking water... she does not drink water at all now [on her own].

According to another mother,

Just to lead his life, whatever happens... if he takes to shop 100 rupees, he needs to know it's hundred rupees, and that much I want my son to have. Not more than that... no mathematical calculus or algebra or anything like that.

More than 50% of the parents ($n=10$) stated that they hoped for their child to *become normal* and be *fully cured*. For example, one mother stated,

I just want her to become normal. I don't think even for a moment that she is beneath a normal child. I think she is extraordinary.... Her brain development is very good.... So, we are fully confident that she is going to become okay. That is why we are spending so much every single day, and taking all these steps for her. We have that hope.

Another mother stated that although she was seeing improvements in her child every day, she wanted for her son to be fully cured.

Improvement...see now I can say my son is improved. See, when you have seen three years back, I cannot even take him in bus and all... now, I can do that. I can take him anywhere and he behaves well. I can take him to the malls and all. But first it was not like that. So, treatments or because of the age he has improved, we don't know, but he has become alright. But I want him to be normal. I want that treatment. Not just that improvement will be there. He has improved... improved, improved, improved... but I want for him to be fully cured.. that is what every mother hopes for.

Some parents ($n=6$) also mentioned themes related to improvement in communication and speech (*only if he talks I will be happy*), while others ($n=5$) mentioned themes reflective of their child's future seeming unclear and worrisome. For example, one mother shared,

So the future of the children is still in the dark. You don't know what is going to happen to them in the future. How long... the parents until we are alive will be able to support them or help them. So we don't know what is going to be, how they are going to survive. In spite of our help in trying to bring them up you don't know how they are going to survive the future. So that is always a thing at the bottom of our heart... that is an insecurity feeling about these children.

Table 12 presents theme clusters related to parents' expectations for their child's future, statement sources and references for each, and exemplar statements describing each theme.

Table 12.

Parents' Expectations for Child's Future.

Theme Name	n	f	Exemplar Statements
Independent living as an adult	16	25	<p><i>This is what I'm expecting. He should have the common sense. How to survive in this world. Cause people around you are going to cheat you if you are going to be a coward. You should be independent and you should know how to carry yourself in this world. This is what I expect from him.</i></p> <p><i>As a parent you want him to be independent. You know the first fear is what happens after we go... So, you want him to be independent. And independence means if he can eat on his own, sleep on his own, be on his own, not necessarily, you don't want to make an Einstein out of him or that he has to brilliant. Anything that he likes to do, vocationally, and which he would love to do... I think if he can be independent, I'd be happy. If he can eat on his own, if he can dress on his own, bathe on his own, be on his own, we'd be happy.</i></p> <p><i>I strive to get maximum improvement, because this is the age we have to bring the child, at least to the, not to the normal level, but at least basic things, self-help and all that.</i></p>
Hope for cure and normalcy	10	35	<p><i>Basically he is a very intelligent guy. If he is gonna to study well, I'll very happy, I'm gonna give him whatever he wants. This is what I expect. He has to be independent. Don't be dependent on anybody. I should say that he should go back to a normal school very fast. And study well and prove himself that he can do.</i></p> <p><i>I wish we could go abroad. People say that this problem will get cured quickly if we get treatments in foreign countries. They say that if the child has a consistent teacher (and not just parents) working with him or her in a school for about 6 months on various activities that a child would need, then we can cure this condition easily in 6 months. I have heard of this.</i></p> <p><i>Yeah, they say so many research is going on this autism... many years ago there was no medicine for cancer, but now you do. So, maybe that is the hope.. that hope is there.</i></p>
Improvement in communication and speech	6	8	<p><i>I want her speech to improve a lot. I think if speech improves, all other activities will really come up well. Now, she has no communication, so she is alone, and probably has a poor self-esteem, since she thinks other children don't want to play with her and she doesn't know how to interact with them. So, I really want her speech to improve. That is the big thing.</i></p> <p><i>Communication must improve at least a little bit. I can understand her, but others cannot. Even if she doesn't have speech, she must develop some basic communication. If it improves a little bit, others will also understand what she is trying to convey.</i></p>
Future is unclear and/or worrisome	5	7	<p><i>I am not aware of how the future for these children is going to be. There is always a feeling of insecurity about the future of these children.</i></p> <p><i>That is my main thing. I really worry that he won't be able to get married.</i></p> <p><i>I don't know. I am just doing my best. I don't know what to do. I will do what I can for him until I am able to do it. After my time, I don't know what will happen. Even my other kids won't take care of him... how long will</i></p>

Table 12 (continued)

			<i>they do it? They can't. So, I don't know what will happen after me.</i>
Hope for some improvements**	3	4	<i>See for these kids, ma'am, every day is one one improvement. My son will not be able to do one particular thing yesterday, but today he is doing it on his own. So tomorrow what can I do? We feel, if we work well, he responds very well to that, touchwood. And, we got the thing.... we work, work, work, he will come up. Only that we have to do. Everything is good... visually he is very good.</i>

** Findings not treated as a theme since there were less than 25% ($n=5$) of statements that fit this theme.

Note: n = number source statements that fit this theme; f = frequency of reference.

Thematic Category: Professionals' Perception of Family Expectations for Child's Future.

Even though they were not specifically asked about it, a theme that emerged from the professional interviews related to professionals' understanding of parents' expectations for their child's future. Only one notable theme emerged in this category, and was mentioned by almost 60% of the professionals interviews ($n=12$). These professionals believed that most parents typically expected or hoped for normalcy and cure, as well as academic mainstreaming for their child (*they all want a cure for their child!*). For example, one professional stated,

Yeah we, uh 90% of parents who come in today, yet have the expectation that their child will get into a regular school. That is what puts me off. Because it is only that for many parents. Only academic achievement.

Another professional noted, *Some parents will tell, my child will study engineering, my child will study doctor, like that also they will ask.*

Other professionals believed that parents often wanted *immediate improvements*. For example, one professional noted,

Yes, some parents are like that. They make us free... okay, he is in your hands now, you are free to do what you want. Some will do home programs and all... some will do that with an interest. Others... well, they want a big change in them, but actually don't understand that even small changes are a big deal for autistic kids. What the thing is, like in a movie, they want to have a good end and that it should come immediately. Like taking a pill and getting rid of your fever. They want immediate improvement.

One professional, talking about how many parents consider special education an interim arrangement before their child transfers to a mainstream school or be cured, stated,

Most of them ask, will it take 6 months? Will it take 1 year? How long will it take? 90 percent of them uh comes with hope. Like he will be cured. Will he be okay? That's what uh the question, they don't know the situation is.

Thematic Category: Parent-Professional Relationships.

Overview. We asked both parents and professionals what it was like working with each other. We also asked them about how they resolved any disagreements that may arise in the course of working together, and if they wished their relationship with each other were different in any way. In addition to participants' direct response to these questions, other statements that they made throughout the interview that were reflective of the parent-professional relationship were coded in this category. With regard to parent-professional relationships, the themes that emerged were notably different between parent and professional groups. For example, while parents primarily mentioned themes that were reflective of trusting, positive, and collaborative relationships with the professionals or a desire for somewhat better communication about their child's treatments and progress at school, more professionals mentioned themes that were reflective of negative, untrusting, and professionally-dominated relationships.

The following sections describe in more detail the thematic clusters that emerged from parent and professional interviews in this category.

Parents. Eighteen parents (94.7%) mentioned statements such as they were *extremely happy* with their relationship with the professionals that they were currently working with, especially in the school-setting. These parents mentioned themes of trust and respect as well as recognizing the training and experience that professionals have. For example, one mother noted,

Basically I leave things to the teachers, ma'am. Because they are more experienced than what we are. They are physically and you know, both in academics and practically also they are trained. They don't see only my son. They see all types of kids here. From the autistic to the minimum level so they know to handle these kids. See it should be one person who has to take the decision, and it should be for the good of the kid actually. But if I'm going to interfere, there is no meaning in me interfering and inside a school issue.

That is not good actually. As far as I am concerned, once you trust them, you have to leave their job to them. Let them do. You sit relaxed. And when he comes home you take care of him.

Another mother noted,

If we don't know something, we ask and they explain. So, there has not been any disagreement. They teach us what we don't know. They have the experience with this kind of population. See, some things may not have worked out for my specific child, because not everything applies to all children. In those cases, they just try something else different.

Yet another mother stated,

If I have to be honest, we have to listen to everything that the school says... I believe that this is necessary and important to do. They only tell us for the good of the child. So we should listen to them. They will only tell us what is good for my son and what he will need to get better. In that case, it is in our son's best interest to do it.

Other parents noted themes of collaborative and positive regard.

It is very positive. Whatever it is, they will ask us, too.... For example, they will ask us for our opinions about the treatment we have just observed, and we will give a written document about that. If we point out something that is not right for the child, then they take our suggestions, and say they will try to do better. In that way, our communication is very good.

Another mother noted,

See, all the therapists available here, they understand the child well, they understand the parents' also, their feelings and emotions toward the child, and they give us valuable feedback time to time.

Other parents talked about professionals treating them with kindness and caring: *Yes, they are all very nice. They all speak well with me. Here we have been very happy with the people we have worked with.* Another parent shared, *the Sir [school director] here especially is really good... even in this one month, he has treated us so well and talks very kindly to us.*

When asked about whether they wished their relationship with professionals were any different, about 25% of the parents ($n=5$) stated that they would like to see improvements in communication between parents and professionals, especially with regard to their child's

progress and the strategies used with the child. For example, one mother noted,

See, if I wish they were more... they would clarify the goals... and then whatever approach they have tried, they can tell you, this is how we've tried, then as a parent I know this will work and this will not work.

Another mother noted,

I wish I could observe what is being done in treatment. Or at least that they would talk to us every day or every week patiently about what has been done with the child in sessions. That would be nice. Right or wrong, negative or positive, I wish they would tell us everything.

Most of these parents, when asked how they might resolve a disagreement that may arise with the professionals, either stated that such disagreements *have never happened so far*, or were resolved *through dialogue and telling them [professionals] about our [parents] concerns*, or they would simply leave and go to some other professional.

A minority of parents ($n=3$) had anything negative to say about their relationships or interactions with professionals, and they primarily talked only about their past interactions with physicians such as neurologists, pediatricians etc. None of these parents expressed any dissatisfaction with the professionals with whom they currently worked, and by contrast, stated that they were *very happy* with these relationships.

See Table 13 for theme clusters related to parents' report of their relationship with professionals, statement sources and references for each, and exemplar statements describing each theme.

Table 13.

Parent Report: Parent-Professional Relationship

Theme Name	<i>n</i>	<i>f</i>	Exemplar Statements
Positive, Collaborative, Trusting	18	68	<i>They have an excellent therapy center here and they have a wonderful faculty here. They take care of the kids so I need not go for another alternative, because I'm very much okay here, they are doing an excellent job so I need not worry.</i>

Table 13 (continued)

			<p><i>Here, we get a lot of ideas about what we need to do for the child and what we shouldn't do. That is very good. We have to be realistic. We cannot expect that she will do everything like talk and read and write because she is so severe. But, we need to know how much she can do, based on her ability and level. For that, the professionals really help. I came with no awareness of autism, but I am so much more aware now because of the help from the professionals.</i></p> <p><i>Yeah, it's a very good experience. I've learned so much about this problem, problem of the children, and about the alternate remedies which we have to compensate the difficulties or to overcome the problems. They're very supportive. We're having, I'm having a good experience. I learn a lot. Yeah... opinions differ, but we used to discuss which one is preferable or right for the child, and we will take it out. It is not that I would deny or was denied anything like that.</i></p> <p><i>We should be fortunate to be here in [school]. It's a very wonderful school here.</i></p>
Need for better communication	5	6	<p><i>Yes sometimes. It's like three teachers here. But with one teacher, sometimes I may not, yeah, I do feel that one teacher is not as clear in what they do than another teacher, they need to be more clear in what they do.</i></p> <p><i>Yes. Telling us this is what she did well or this is what she didn't do well. Or, they could at least write every day in the diary that they have given us. Because they tell me my girl doesn't sit in class... so it would be nice to know every day how long she sat for that day.</i></p> <p><i>It will be nice if we get more chances to meet with them, apart from just the monthly meetings, though.</i></p>
Paternalistic, Negative, Unreceptive to parent concerns**	3	11	<p><i>You know what happens, normally in our country, the doctors are treated like gods, and so you go and you say, ok it didn't work, and they kind of look at you and say who's the doctor here so..... I have, plenty of times, most of the times [it has happened]. So.... because.... I wouldn't say they get threatened, but I think they are probably not used to anybody questioning so they find it very hard to handle people like me.</i></p> <p><i>And, again they feel that they are the only one who can bring him out of it and they do not accept the other therapy also. And I also tried telling her, I think we will try some special school for him, but she said no no we don't need that for him, so it was not like a teamwork... they felt that they were more the experts and only they can do everything.</i></p>

** Findings not treated as a theme since there were less than 25% ($n=5$) of statements that fit this theme.

Note: n = number source statements that fit this theme; f = frequency of reference.

Professionals. While there were a few themes that emerged from professional interviews that were similar to parent themes (e.g., positive, collaborative, trusting; need for better communication), there were other themes that were quite different. In general, unlike the parent themes, no one theme emerged clearly as primary; on the other hand, the same professionals mentioned many of the themes and thus appeared to have a mixture of views about parent-

professional interactions regarding a child's autism.

About 70% of the professionals ($n=15$) mentioned themes that reflected a directive and professional-driven relationship between parents and professionals. This theme indicated that professionals made the ultimate decisions, were hierarchical in their relationships with parents, and sometimes viewed parents as uninformed or in need of education about autism. This theme did not reflect a necessarily negative attitude toward parents; on the contrary, many of these professionals were in general positive and respectful in their approach to parents and were thoughtful and sensitive to parents' concerns. For example, one professional stated,

. . . mother only used to come to here, used to be very frustrated, so weekly once we will do the counseling to the parents, regarding the level of the child, what they have to do, so they frustrated, they have...with lot of problems they will come here, so we have to do counseling. Counseling is one of the main treatments for parents. So, I like to do counseling with the families to take decision.

Another professional, when talking about how she explains the initial diagnosis to parents stated,

This is the example I give them, which they are able to understand, because I have to go down to their level. I tell your child has got it; he doesn't know how to use it; that's not his fault or your fault. It is developmental. "Why should it happen to my child?" [parents ask], I say, I do not know. They say, "will my child become all right?" I say, "let's wait and see. See it's not in our hands., I have seen better children become worse and worse children becoming better. Let us starting intervening as early as possible, early intervention." I'll tell them, "wait and see, wait and see."

About 60% ($n=13$) of the professionals described their relationship with parents as being primarily positive, collaborative, trusting, and open in nature. They expressed genuine concern and empathy for the parents, and often described the relationship between parents and professionals as being *emotionally close*. For example, one professional stated, *see one thing is...in our set-up, unlike a professional in US, here we go a little bit closer [to patients]. The emotional attachment definitely plays a role [between parents and professionals].*

Another professional noted,

That's how it is always. Because there is so much of an emotional connection with teachers and therapists and everybody. Parents feel it's family, they come here running. You know they are like, 'will she like it?' Is it ok to say something, is it not. So they are thinking very emotionally as well.

Some professionals talked about the importance of considering the family's needs and priorities when working through a disagreement. For example, one professional stated,

... the family is the first institution providing services for the child. Not the center. So unless the family understands and the family accepts the child, uh we whatever the services we are providing is no meaning, one. And, second thing is the services what we are providing is only a time-bound and we not we don't know how long it is going to be continued. But the services provided from the family, the support, the encouragement and the everything from the family is playing a very important role in child's growth and development. And, the family is the primary institute or the union or the institute or the agency that needs to understand the child's problem in the right way.

Some professionals expressed their positive regard and sense of empathy for parents and their challenges.

... when I look at the parents, many of them I feel a deep deep respect for them. It's because it's easy to say you know...I'm doing this, I'm doing that, but the end of the day I am going home. I'm not going home to a family that has a person with autism or any other disability. These people have to bear with it lifelong. And I have full respect for them. I ... it's easy to say see I'm doing this in school and you're not following up at home. But now I have realized you know it's easy to say 'I have done so much.' But it's the parents who are doing so much for their child and who have to bear with everything. So I have a deep respect for the parents.

Several professionals ($n=12$) mentioned themes that, explicitly or implicitly, reflected relationships that were more negative, untrusting, and un-collaborative in nature. Statements that were coded under this theme included comments from professionals about their frustrations with parents for not following-through with treatments and professional recommendations, having unrealistic expectations from treatments and for their child's future, and which conveyed the professional's sense of impatience in dealing with parent's personal challenges and problems. For example, when asked what it was like working with the parents, one professional stated,

I am sometimes so frustrated, I give up, you know... you get tired. Some mothers drain you down like anything. We are exhausted at the end of a 15 minute session with them... they will just keep shooting questions and they are not happy, and you are just fed up.

Another professional noted,

It is a challenge. It is a challengable one. There are some parents who are mature enough to understand the problem and they cooperate well. There are parents who have their, they express their own problems, and they do not cooperate. So, it is a tough job for us to convince them to participate in treatment.

One professional, describing how they resolved disagreements, stated,

I will make them to agree. If I am saying that your child is having this problem, if they are not agree that, then I will uh I will ask them to sit in front of me and show the activities of the child, and I will make them to agree. Because most of the things are behavior problems. So we will explain to the parents; if they not agree that my child is not autistic or something and we will explain them with demonstration, so they will understand and then they will agree.

Some professionals ($n=9$) expressed themes that reflected views that were more ambivalent or mixed in nature (*some of them are troublesome, most of them are nice*), while others ($n=7$) expressed a desire for better communication and boundaries between parents and professionals. For example, one professional stated, *actually, both interactions from parents and professionals should be clear in understanding, and parents' beliefs, parents' conditions must be understood by us.*

See Table 14 for theme clusters related to professionals' report of their relationship with parents, source statements and references for each, and exemplar statements describing each theme.

Table 14.

Professional Report: Parent-Professional Relationship

Theme Name	<i>n</i>	<i>f</i>	Exemplar Statements
Directive, Professional-driven	15	29	<i>I tell them very clearly... you may find me a little bit strict; it's not for my sake. Unless I am strict, you are not going to complete this. If you want to get my help, please follow whatever I say. If I am not helping, then it is your wish.</i>

Table 14 (continued)

			<p><i>No, no, absolutely not [parents cannot select their own treatments for their children]. Because it is very clear that this is what we are offering, this is a school, and if you want any other treatment, you are welcome to go elsewhere. If you want, like the Indian medicine or any other treatment, they are welcome to go.</i></p> <p><i>Actually, we make them to realize the need of the child, and then we make them to understand why we are choosing those, that treatment, and then we ask them to accomplish that.</i></p>
Positive, Collaborative, Trusting & Open	13	57	<p><i>If they understand the child's problem is a medical condition, they will go the hospital. If they understand that the condition is a disability condition then they'll take the child to the rehabilitation center. See, if they understand the child's condition is due to God's, destiny or something like that they will not take any kind of service, they will keep the child at home without doing anything. So understanding of the child's problem only take the, make the parents to react the right way. So family playing an important role in any services whatever we are providing. We may provide the best, uh best services in the center but if a family is not cooperative then there's no meaning and success in your service. So family is very important in the process.</i></p> <p><i>Yeah most of them you know, like they are waiting for person to share your.. so. when you are like a receptive for their problems, most of them I feel are very comfortable to work with.... If parent is ready to work and parent is ready to accept, and if we are ready to receive, you know, really...you should be a good listener, and you should be...and you should be very receptive. Then the teamwork will really work.</i></p>
Negative, Challenging, Untrusting	12	30	<p><i>There would be a couple of parents who... it is very difficult to get through to them, because they feel... their priorities are different, they feel that, once that the child is admitted to the school, it is the school's responsibility to take care. And, they do not play any role in that. So, there are couple of parents who have that attitude who feel it is the school's responsibility and not our responsibility. I do not know if it is because they do not have the time, because the treatment will be so expensive that both parents have to work. So they are so busy in working they miss out on spending quality time with the child. In spite of our telling them, counseling, explaining situations to them, they still... there are a group of parents who do not cooperate.</i></p> <p><i>Not many people are cooperating I feel.</i></p> <p><i>Most of the time the parents withdraws, the parents withdraws from the person. Even here when we have put our foot down and we have told certain parents it's not the right thing to do, most of the time you see parents just taking their children off. Because they feel ok you know they don't want to do what I want to do. Most of the time the parents just pull child out.</i></p>
Ambivalent or Mixed feelings	9	12	<p><i>It really depends on the motivation level of the parents. Even in some lower SES, if they are very concerned they may do. Mainly it depends on how the parents mindset is. Like some parents they don't have time, or they have another child means . . . they won't do. So it depends on the parents also...</i></p> <p><i>Well.. it is... there are days, times I kick myself for having started this. (laugh) There are other days when it is very gratifying because you see something, you know, something, something maybe really small but something that has happened, or which makes you think...they are kids and</i></p>

Table 14 (continued)

			<i>you know they are like any other child after all. We often forget they are kids. We always treat them as kids with autism. So when they show something... you know it's so cute it's so beautiful.</i>
			<i>Each day is different. Some days I am very happy, because I made a child better and the family is happy. On the contrary, I am sometimes so frustrated, I give up, you know... you get tired.</i>
Need for better communication	7	9	<i>They expect something; they expect immediate improvement and changes, or getting medicines. Sometimes, their expectations is only to get medicines for their child, sometimes, and when we say that there is no medicine for such condition and we only have to go for training or practice, sometimes they, you know, they hesitate to take this advice. So, there we wish it were different. It takes some time, and then they come back, it takes some time for them to get convinced.</i>
			<i>Oh I mean different in the sense, I mean I want it to be open that is it. If the parent has some disagreement, I wish them to come and talk to us in person that's it. We don't want them to air it to some [other] professionals which will never give us an opportunity to sort it out.</i>

Note: *n* = number source statements that fit this theme; *f* = frequency of reference.

Thematic Category: Professionals' Views about Families.

A separate theme that emerged across all the professional interviews involved their views about the families that they worked with. This was an important theme that emerged from the data and was gathered from the different statements that professionals made throughout the interview as well as their response to questions about their personal beliefs about causes, their perception of family beliefs about causes and family expectations for the child's future, the professionals' experience of working with families one-on-one, and their outlook and approach to resolving disagreements that arose with the families. Memos and notes documenting the investigators' overall impressions of a professional based on their responses throughout the course of their interviews also served to inform this thematic category (see Table 4 on Professional Characteristics).

Emergent themes in this category suggested that most professionals held a mixture of positive and negative views about and attitude toward the families that they worked with. More than 50% of the professionals (*n*=12) mentioned statements that indicated their empathy and understanding of parental stress caused due to their child's disability. For example, one

professional, describing the kind of emotional struggles that a parent goes through after a diagnosis, stated,

Maybe most of them wouldn't come out but a lot of them would blame themselves, because at some point of time they do blame themselves. There is a feeling that I, especially mothers, more than fathers, having the guilt conscience. Mothers feel that since they have done the whole process, you know the physical process of giving birth, that you know they are you know responsible for what's happened. I feel mothers take more responsibility than fathers do. They blame themselves; they feel it is their mistake, that's why it has gone wrong. And like I said, grandparents blame them, you know, the daughter in law. The father says, okay it is your problem, not mine. Everyone starts blaming the woman, and she starts believing it. Okay, maybe it is my fault.

Another professional acknowledged the frustration that parents often experience as a result of the amount of efforts they invest in their child's treatments while still not receiving any definitive answers about how much the child will achieve:

They really feel frustrated and disappointed, they really get bogged down by this because we insist on intensive therapy, we insist on this kind of regime and special protocol, but at the end of the day we say we cannot cure, it really frustrates the parents. But, as they walk along the journey, they tend to understand the value of what we said. We said near-normalcy meaning, it can be 99.99% also, it can be 80% also, it can be 60% also... so, they start valuing these words later... later when they walk along the journey, but not during the initial times. They get a heart break when they hear this.

Other professionals ($n=12$) made clear distinctions and judgments about families' based on their level of education, income, and social class, and there was a good mix of views about which socioeconomic "class" was easier or more difficult to work with. For example, one professional stated,

Uh again, uh social values play an important role. Uh parents who have uh who have been given education have to be a lot more open to this topic, but it is not necessarily like that. Because I see parents who are well educated, who have gotten into the best of universities and come back who yet believe, you know, there is a cure, there's something which will come up, and you know.... it is and they want to, I've seen parents who have been embarrassed to take their children out. All the so-called well educated family we are talking about? Yeah, they feel embarrassed because the child is hyper, he is going to run around, he is going to blabber certain things, and the parents feel ok no I'm not ready to take my son out because it is an embarrassment for me.

Another professional believed it was the less-educated families that were harder to work with.

If they are well-educated they can... if they are well-educated they feel ok, it's quite ok, my kid has it, but what do I have to do... like that they will talk. The middle class and low class peoples, what did I do so that my children is getting like this. Like, they feel like that. Depends upon the classes. If they are quite educated, they understand it is because of this, that and all. We can't explain, particularly we can't explain that this is the cause. They understand if you talk with them they understand. But with the middle class and low class people they don't understand. Whatever we tell them, they won't understand. They think in a way that I did something wrong, so that it comes like that. Like a curse, it's like a curse or something like that.

About 60% of the professionals ($n=13$) also expressed the view that most parents were uninformed, unaware about autism, and gullible to being cheated by professionals proclaiming a cure for autism and that they are *often victimized*. Sometimes professionals expressed sympathy and understanding about this behavior while others expressed frustration. For example, one professional noted,

I guess autism is the most expensive of conditions in India. Because... and I think, families with children with autism are the most exploited lot. It's a fact. All kinds of quacks, quackery, and everything [treatments] is sold on the claim of being one-on-one, and uh, curing, and working on people's ignorance about the condition, and it's a market. It's a market. People spend up to 20,000 rupees a month, and that's a lot of money, and not just people who can afford it. People actually take loans and do this. And I think it's criminal. They can save that money for the child's future, because this child will need a lot of money once the parents are gone.

Another professional expressed more frustration with parents becoming easy “victims” or being cheated easily: *I know parents who have been mad and have gone and spent you know like loads of money not knowing whether it is you know reliable or not. So that's a big difficulty we have with parents.*

Other professionals endorsing this theme mentioned parents being unaware and uninformed about autism, and thus approached families in a more directive and authoritarian manner. For example, one professional stated,

The parents has to know that what we are teaching to the child and what we are doing to the child, and what we are working on. Which level and which goal we are targeting. So that they have to know, and after going their home, they have to implement to child. They have to follow it. So, if it is Saturday Sunday, it is holiday for us, so they should not make any [changes? unclear], they should implement their goal there also.

Notably, only about 40% of the professionals ($n=7$) mentioned themes that reflected views of families and parents as being aware, well-informed, and well-educated. These professionals also tended to be more actively collaborative with the parents and seek their opinions and input about treatment decisions and implementation. For example, one professional stated,

But today, parents who come in are much updated with the current happening. When we have.... when they come in for an interview here, they want to know what are the facilities available, because they are well-read compared to what it was four years back. Today parents are much well-read, the intervention program starts much earlier.

Another professional noted,

Training on autism. . . . if they have undergone training, then definitely we should respect that. Because yes, they have got some knowledge. Let us share with them, let us know what they are trying to do. Maybe that can help me to improve the quality of services for the child.

Table 15 presents themes and exemplar statements for this category.

Table 15.

Professionals' Views about Families

Theme Name	<i>n</i>	<i>f</i>	Exemplar Statements
Parents are unaware, uninformed, and gullible	13	26	<p><i>Yeah. So, they guide them to where to go about for the next move. Sometimes, even being a psychologist, I too do that kind of counseling with parents. What is the need and importance of the intervention, because sometimes many parents are not aware that their child requires intervention or treatment. So that part I do it.</i></p> <p><i>Anything, be it Ayurveda or yoga or siddha or anything... parents go blindly and fall in to it. Be it any social economic status. Of course the more educated withdraw themselves, because they kind of use their discretion to say ok, is it okay or not okay. But most of them fall into it. It's like again... parents group talk and everyone gets persuaded in to it and fall in to it. So that's something we have seen.</i></p> <p><i>They need to be uh awareness. They want to get awareness regarding the</i></p>

Table 15 (continued)

			<i>autistic child.</i>
Empathetic and understanding of parental stress	12	22	<p><i>Majority of the people...even if they are not willing, the mother-in-law will tell. A neighbor will tell. Naturally they will like to.... because you know pretty well there is no immediate improvement and it's a living dream. Their dream is shattered the moment you make a diagnosis. So they would like to go to everybody and anybody to get some result. They do go. They go for doctor shopping, they go for all sorts of investigations, they give all kinds of medications, they go to alternative medicines, and then they go the 'poojaris' (priests) and other people; you can't do anything about it. Whatever you can do, you can do.</i></p> <p><i>They start crying, they get upset, but again I tell them, together we will try to overcome this. It takes time for them to get used to it.</i></p> <p><i>World only surrounds among the child, you know, they haven't had a social life. A lot of parents who don't socialize because you know it's only them, the child, they see it as a burden... Of course they won't use the word burden because it's uh... you know 'how can I say about my own child' you know... but you realize they don't want to socialize, they don't want to go out, and they just want to be by themselves. And with the son. And with time you'll see it is depression. And there are bound at home. They have a routine. Because the child has a routine, so they have a routine, and you know you realize by observing them. Parents who come in to school, they look dull, they don't dress up, they don't take care of themselves, because this is the only thought that runs in their head all the time. And, to deal with expectations.</i></p>
Issues related to income, education, and social class	12	38	<p><i>So rich family they will do, they will do whatever we say. They will do all the interventions in their home also because they are educated. And the middle class and the poor class I don't think they will follow all the activities in their home. Because that rich people they are educated. Their education is good.</i></p> <p><i>They are not able to accept it. I am a software engineer, my wife is a software engineer, I am a professional, how can we have a child like this? Whereas a child who is coming from a village, where the entire village stands by, I trained you to become a skilled worker or semi-skilled worker or a farm laborer, it is more than enough for him to lead a normal life. The other members take care of him with the things they have.</i></p> <p><i>Actually, expectation from the parent will always vary. Like, when they feel they are well-to-do [wealthy], they might come and speak with more awareness. They would have approached many people, they would have read some statistics and all. So, they will come with more expectations and talk to the professionals. It is opposite to low SES.</i></p>
Parents are well-educated and well-informed	7	7	<p><i>The thing is, well-educated people, if you see them at a time, they will look up the internet. They will see all the reasons and all. They will look at the reasons and then only they will come to us. Even before we tell them about it, they are well educated about the condition...</i></p> <p><i>Parents belonging to higher socioeconomic status definitely read a lot. They come with good knowledge about their child's profile. They would have consulted many professionals before coming to us, and they will be very concerned about their child's problem.</i></p> <p><i>But the parents in my class are very educated. They are well aware.</i></p>

Note: *n* = number source statements that fit this theme; *f* = frequency of reference.

Professionals' Beliefs about Causes and its Impact on their Views about Families. One theme that emerged from the data in terms of factors that influenced professionals' views about families pertained to what professionals believed were causes of a child's autism (see category Beliefs about Causes: Professionals), as well as their perception of family beliefs (see category Professional Report of Family Beliefs). Seven professionals held beliefs that, in one form or another, reflected that autism was caused by parental neglect of the child's emotional needs (e.g., cold parenting, moving to a nuclear family set-up) or a combination of organic and parent-related factors (*Genetic, one is genetic. Another, the environment plays an important role. Environmental attention is not there*). Out of these seven professionals, five held negative views about the families in general (*they are frustrating and difficult to work with*), viewed parents as uninformed and unaware (*they are usually not in a position to decide about treatments, they don't know much about it first time*), and adopted a more authoritarian approach with the parents (*I will make them to agree with me*). Further, these professionals also perceived families as endorsing similar beliefs (e.g., parental fault, maternal stress during pregnancy, moving to nuclear family set-ups) as causes of their child's autism or perceived most families as *not knowing* the cause. Only one professional out of the seven who believed in parental factors as a cause of the child's autism in one way or another had an overall positive view of the families and a more collaborative approach, while the other remaining professional had ambivalent views and was mixed in his approach to working with families.

By contrast, in the other group, where professionals reported that they *do not know* what caused autism ($n=1$), or that they did *not care about the cause* ($n=1$), or mentioned themes that reflected beliefs in more scientific causes endorsed in the literature (e.g., genetics, a combination of genetics and environment) ($n=12$), only one out of these 14 professionals held an overall

negative view about the families and was authoritarian in approach, and three held mixed or ambivalent views about the families and were mixed in their approach (i.e., sometimes collaborative, sometimes authoritarian). The remaining 10 professionals had overall positive views about the families that they worked with, and made deliberate and consistent efforts to be collaborative with the parents during diagnosis, assessment, treatment planning and treatment implementation. Further, even though these professionals were sometimes directive in their approach, they were sympathetic, kind, and thoughtful when speaking of the families and parents.

Thematic Category: Autism in India.

Overview. We asked parents and professionals how the community reacted to children on the autism spectrum and their families. The themes mentioned by parents and professionals were highly consistent with each other and included themes related to the need for more awareness and resources in the society, problems with resources and accessibility, growing awareness and understanding, society as rejecting and critical, and society as supportive and accepting. A majority of the parents and professionals acknowledged that there were problems with resources, expenses, and accessibility to services for children on the autism spectrum and that there was more need for awareness, acceptance, and understanding in the community. More parents than professionals reported that society was rejecting and critical, and fewer parents than professionals mentioned any positive themes such as improvement in awareness, acceptance, and resources, or viewed the society as supportive and accepting. The thematic clusters that emerged for both groups in this category are discussed in more detail below.

Parents. More than 85% of the parents ($n=17$) mentioned that there was more need for better awareness and acceptance, as well as for academic mainstreaming in the society. For

example, one mother talking about the need for academic mainstreaming stated,

I think basically they should all see them as normal kids. That is most important. Even if they have any disabilities, they should not ban them. That is what I say in the normal school. They have to bring a special wing for special kids. Where they have to sit along with the normal kids and they should also be trained in the same way. Any difficulties, the special educator has to come. They should see them as a normal kid. That is more important. That is what I expect from society actually.

Another mother, talking more broadly about acceptance in the society noted,

The first thing is that the public can stop staring at the kids. Yeah. And, go this, go that, some unwanted advice, some unwanted interpretations will be there, like you could try that, you could do this. Or take your child here and there. Some people might hesitate to mingle with the family or they will tease the family. I don't have that, but people used to say that this is happening to my family, my daughter and all. Society can avoid that. That is most important.

Still other parents noted concerns with a lack of awareness of autism in the society as well as among physicians.

We need a lot more awareness. They are able to diagnose autism now even at 2 years of age. Lots of parents don't know what symptoms to look for. They are only able to identify that the child does not talk, but they don't know about other symptoms. That is not their fault. Only if more awareness is created, can early diagnosis be possible and only then can we intervene early and increase improvements in these children.

Another parent stated,

For me the only thing... even the doctors should be awareness... even if you take for orthopedics, they treat him like one 'janthu' [word that describes an object or a being with no feelings and that is not human], if anything injury happens or something, if you take them and tell them 'special kid,' immediately they will pull them aside and get two nurses and put him on the bed like that...

Less than half the parents in the sample ($n=8$) mentioned themes that reflected an improvement or increase in awareness, acceptance, and resources with regard to autism in this southern Indian city in recent years. For example, one mother stated, *now it is better, awareness is better. Everyone is able to recognize that if we start early, improvements will be better for child.*

Another parent noted that physicians were also becoming more aware: *Right, the good*

thing now is ok... if I do need to take him to a pediatrician now, when at least I say the word autism and they know what I'm talking about.

One parent specifically spoke about this city as being one of the few cities in India where parents and children had more options and availability with regard to treatments for autism.

I think generally [city] is very good, as far as you see schools... I think even in [another city] and [another city] you don't have...special schools.. especially, you know... you have special schools, but everything will be mixed. Here in [name of city] you see, this is only for autism. Then you have... there you have the open school for LD children. And, facility... [city] has got the best medical facilities in India. Not only India, abroad also. We have the best doctors. Everything is good here. I have no complaints about [city]. Because we have people who are really working hard, and we have lots of facilities over here.

About 85% of parents ($n=17$), however, mentioned themes reflective of problems with resources, expenses, and accessibility to services for children on the autism spectrum in the city. Some parents talked about *the big dearth in professionals in our country*, while others spoke more specifically about their personal challenges in gaining access to services. For example, one mother stated,

Now see, things like... he has a lot of sensory problems. I know he does need more occupational therapy or more..... but unfortunately for us we have a time constraint. By the time I leave from here, it's 5-ish, and we stay about 25 kilometers from here, so if I want go elsewhere you know, it becomes too much. Like he's.... it's no use taking him because by then he's totally exhausted, yeah. So if things were there, which are close by or you know which are more methodical, say, ok you can do it during vacation time or it can be done twice a week, you know, sensory things... Because after all, there are, and the school has a budget as well. And they can give them SI only twice or thrice a week. And he needs more than that. And he is a child that needs it now. Now there are other children don't.

A mother of twin daughters with autism shared with us the extremely difficult life circumstances they lived in that led to financial hardships and difficulties with accessing services.

Yes, it has been difficult. I don't like this city. We can't speak the language, we only speak Hindi... we don't have a good job [husband]... and people say it will be difficult for

him to get one, because he cannot speak [regional language]. So... it has been difficult. For the last year or so, he was only doing odd jobs. But, now, he has a different lead. Hopefully, that will work out. Actually, he is going to apply here in this school. One of the professionals here encouraged him to seek something here... since we have two kids with autism here, we don't have money, and we also have another child who needs to be educated. So, they asked us to seek for help from the director here. Maybe a gardener or something. Let's see.

Yet another parent talked about how although fee for services was reasonable in her child's current school setting, it is more expensive in other settings: *Here? Here, the school is okay, the fee is normal. But otherwise if you go out for any therapy I know it's expensive here in India. Speech therapy or OT or anything, it's very expensive.*

Many parents expressed frustration that the Indian government was *not doing enough* for children with disabilities and their families. One mother stated, *the govt. needs to do more for these children and take better care of them*, while another mother, who had moved to the city from a Western country noted,

The government should, like what I saw in [country], the government should...there should be a system, a total system. And there should be a child development clinic, or a pediatrician to whom we can go. And, so it is like, if they diagnose, that is it, they have to get a special school... it should come normally just like that, without the parents going and finding it all out.

Many parents (n=16) shared with us the rejection and criticism they faced from their society and community. One mother, telling about an experience with her neighbors when she once visited their house with her daughter, shared,

... they looked strangely at her and seemed disapproving... they clearly didn't like her behavior. That made me feel very bad. I didn't say anything, but I could see that they were evaluating my child with the normal child who was there, and I am sure they were thinking badly of my daughter. So, in that way, the society really hasn't been very supportive, and they don't seem very aware of this problem.

Parents often shared that people in the community *stared* or *laughed at* when they were out in public with their child with autism which caused them pain and a sense of isolation. One

mother clearly stated,

My child is not accepted. So because he makes some sounds, everybody is going to look at him. So he's now growing old. Before it was okay, he was a small boy, so okay... maybe [society will think] naughty boy or something, but now people make fun of him, they laugh at him.

Another mother tearfully shared,

They stare at us like untouchables. [She is crying here; long pause]. If we had money, none of this would happen... they won't treat us this way. If we had a big house, then we could keep the child in that house and have all the treatments done for her at home... but we are poor. We have to live in the society. We live in a housing board house [govt. provided free housing]... there are 16 houses in our flat. All 16 houses will ask us questions, will stare at us... we cannot take her to any of our neighbors' houses... she is not welcome anywhere because they worry she will break their things. [she is crying a lot throughout this answer, and answers between sobs].

A minority of parents ($n=8$) mentioned themes that reflected views of the society as being supportive and accepting. These mothers mostly referred to their immediate neighbors or drew from personal experiences of people that they have interacted with as being positive and supportive. For example, one mother was grateful for the support from her immediate community and acknowledged that it is not always the case.

The apartments we live in is quite good... people are very nice, because they understand. Sometimes my son misbehaves quite a lot... like, he will go and tamper with their vehicles, he broke the glass of my neighbor's motorbike once. At that time, some of them told me to be more carefully watchful of my son. But they didn't say anything else. If this were some other place, they might have asked us to leave the place. So, that way it is good. Now, he is also better behaved.

Another mother speaking about the culture as a whole observed,

And some people are very friendly. Sometimes when I'm having a problem with him, on the road, some people offer to come and help. Basically they, they don't totally avoid, some people offer to come and help, and when he becomes unmanageable. So I think that only here people are so helpful...

Yet another mother noted,

Socializing is more in India... we have got festivals, we have got get-togethers and all these things... we have gotten this joint family in many places. So everywhere the people

are going and everything... when we go there, they are helping... because with autism child, it is very difficult for his mother to do everything.

See Table 16 for theme clusters in this category.

Table 16.

Parent Report: Autism in India

Theme Name	n	f	Exemplar Statements
Need for more awareness, acceptance, and mainstreaming	17	60	<p><i>In a normal stream, but under a special educator's guidance. Something that should come up in India. That is not there and that is a service that as a mother I am expecting. So that they are not banned as a special kid. Something like that.</i></p> <p><i>We need a lot more awareness. They are able to diagnose autism now even at 2 years of age. Lots of parents don't know what symptoms to look for. They are only able to identify that the child does not talk, but they don't know about other symptoms. That is not their fault. Only if more awareness is created, can early diagnosis be possible, and only then can we intervene early and increase improvements in these children.</i></p> <p><i>It's not, I mean, it's been hard. I mean, I wouldn't want to brush over that... it's been hard. Firstly because awareness level is so low. I think awareness must go up, so much more. Awareness has to go up. And number 2, I see a lot of children who are not as privileged or as ... who don't have certain advantages that my son has, there are a lot of children who don't have all that and I mean, I see their lives... especially now that I'm here and I've seen other children, they deserve better.</i></p>
Problems with resources, expenses, and accessibility	17	72	<p><i>Yeah, I wish there were more schools like this. It's just one one of them in the country right now. There are not very many like this.</i></p> <p><i>Auditory integration, something like that. Some things are not available, not yet here. So, services there is no set form the govt. The parents they take it on their own and find out and everything.... And yeah money, uh, mostly parents only have to pay. So this is difficult for poor families.</i></p> <p><i>See, probably generalizing, people do not get enough financial support or educational help for such children. It's not that, you know, many children they are unable to afford these services. For treating and improving children. And not many parents are educated enough to train and bring up the children. That is a major challenge. Because as such in India I have read there are only a few societies or helplines available for these children. Some kind of plan, programs, some institutions for the children to come up to, what you say, to bring up these children until they become adults. Yeah... what we hope is a secure and protected environment for them in the future.</i></p>
Society is rejecting and critical	16	49	<p><i>They are critical, I feel very bad about it. So, I try not to take it to heart...</i></p> <p><i>And many parents to be frank... some parents are quite negative. They say that we got this child, it is a very bad thing. Our society is... and the thing is if you tell them the problem they don't understand it so nicely, so that is why I thought ok I will just tell them that he doesn't speak. That is all I say and I just take him away. ... when I take him outside you know if they don't</i></p>

Table 16 (continued)

			<i>know about his problem, many think that we have not brought up the child in a proper way.</i>
			<i>Society is different. Some... still they... that's what awareness is not there, so if you say autism, they think that it is a mad child... that is there. They don't segregate between LD or autism or anything like that. So society needs awareness... if you tell "special" means, they think... as if they will come and hit you. That awareness is not there.</i>
Improvement in awareness, acceptance, and resources	8	14	<i>Now it is better, awareness is better. Everyone is able to recognize that if we start early, improvements will be better for child.</i> <i>Therapies which we have alternate, like alternative type medicines... Ayurveda, Siddha, like that, we have other alternates. That is definitely helpful. Because we can try like this massage and all... we can try like that. And there are other therapies.</i> <i>And I have lots of friends from London, from Singapore, all coming and settling down in India just for their son's problem. Because basically what they say is in foreign countries, the treatments are going on a very slow pace. That is they have to wait in queues, but here you just walk down into the classroom. You get an admission, you get better treatment.</i>
Society is supportive and understanding	7	11	<i>Well, our immediate neighbors know that he has this condition. So no one will be critical of him in any way. They are very understanding even if he gets up to mischief, because they know he doesn't do it on purpose. So, they are very understanding.</i> <i>They do sympathize with these kinds of children. No one makes fun of him or us. They also feel bad that the child has a problem like this.</i> <i>Yes, yes, neighbors are supportive.</i>

Note: *n* = number source statements that fit this theme; *f* = frequency of reference.

Professionals. Similar to parents, a majority of professionals mentioned themes that reflected a need for more awareness, awareness, and mainstreaming of children with autism (*n*=16) and existing problems with resources, expenses, and accessibility (*n*=20). For example, one professional commenting about the need for raising awareness in the community stated,

uh I mean you know autism is very very new entity for our country over here you know. It still now it is under the banner of mental retardation. The government has not given a separate [unclear.. license?] for autism. And, then I personally feel is that social awareness is not up to the mark over here. So that you know child couldn't any help from the society as such.

Another professional noted,

Umm... handful of professionals really know the classification and have in-depth knowledge about autism and how will they progress and what will be their future, and things. But by and large, most of the pediatricians really lack knowledge about this. . . . It is a very big challenge. I think a lot needs to be done, lot of work is needed. This is not

enough. That is what I whole-heartedly feel. Whatever we do, we are trying a bit... but we are not full-fledged or knowledgeable enough in this field.

Twenty out of 21 professionals (95%) also talked about the problems with accessibility, resources, and expenses for families, as well as for their own access of other treatments that they desired to use but were unable to do so. One professional talking about more rural parts of the state observed,

Fortunately for me it is not a problem, I am sitting in the city. I am associated with so many organizations I am able to get most of these things. But it's not the same for everybody. . . . For me it's not a problem but it's a problem for most of them. I can't do this if I go to the rural area; I won't get it. Here I have network.

Another professional voicing a similar view stated,

So we are conducting a lot of research in the areas of very scientific and very high research, where the country's educated population is very less, and 70% of the population are living the rural and tribal areas. Ok, these are the aspects that cannot reach to these people even if you do research for another hundred years. So we need . . . where people can get the services or the knowledge from the 'single window system'. Like a primary health care center and a village health center.

Some professionals talked about the lack of proper infrastructure, knowledge, and resources for professionals in the community in order to help them gain more information about autism.

There is no school in India where I can go and look in to and say, okay, this is TEACCH and this is what happens and maybe I can use it in my class. Since there is no faculty available in India who can tell me this, I have to make a personal trip there [to the US] to find out what it is. See the problem is we don't have criterions. Like, say, I want to refer a child to a particular doctor. Which doctor do I refer to? Do I have a database? Saying that 'he is okay a specialist in this area?' No, I don't have that. So we don't have networking.

Some professionals also talked about treatments that they wished they could use but were unable to do so due to problems related to expenses and training. For example, one professional stated, *but it's not like...we are not a strictly ABA, like DTT kind of center. It's very hard to run something like that in India because we don't have so many qualified people to do that.*

Another shared,

... we are now copying everything from the West, we have very little indigenous program for autism. Because there is very little work, professional work and research and studies being done in India. We are all copying what has already been done in the West. And there are schools following TEACCH program, and schools following Options and Miller method and Greenspan. Somebody goes and does the course, then they say it is Greenspan, but it is not fully that, as no one has the infrastructure or the full training to run a school like that. But I am sure that there could be something which could be completely Indian and very effective, which is based on our environment.

About 65% of the professionals ($n=14$) also mentioned themes that reflected an increase in awareness about autism in the community and increase in resources. One professional stated,

When we started 10 years ago, the awareness was very very poor. Nobody even knew about autism. The doctors didn't know. Forget the lay person. Even the doctors, you know, were not very much aware. Now, the situation is much better. Is much much better. . . . The TV, the media is talking about autism, and so I feel it is... when I compare, you know, 10 years ago and now, a big big change.

Yet another professional shared,

It is it is... lot better. Actually, initially if you see, number of autism clients were not even coming to the picture of our survey and all. It was that meager. But, now if you see, with kind of awareness about autism, we are able to admit more clients with autism... that is autism, autism features, ASD spectrum.... When compared to earlier. So, now we are getting quite a many interesting case and clients. So it is now... that means awareness has been reached, no? So, even children 2.5, 1.5, have also come to us. So, that early education is also there. So, it is good. Quite a long way we have come.

One professional talked about the passage of an important policy, the National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act, 1999 (amended in 2000), also referred to as the 92-94 Act, and its role in raising awareness about autism in the disability sector in India.

Very much, very much in the disability sector because many of the universities and institutes are coming up with lots of special education courses. Particularly on autism because autism and deaf-blind—these are the two main disabilities which have come across after this 92-94 Act. So, many people are doing that. Hope that many people come and try to do more services to children with spectrum conditions, and so that at least they get a good therapeutic intervention so that their future looks bright.

Another professional commented in general about the increasing number of resource centers and special schools dedicated to children with autism in India.

I'm very sure now there are some private agencies have started promoting awareness toward autism. . . . They have already established centers for autism, and we have centers, some NGOs supporting the cause for autism, supporting these children with special needs. They want the services to be expanded to the rural areas, they want the community to know about services available for these kids. And since there is now the awareness promotion and government being sensitized towards disabilities, all these things are happening. We are expecting a bright future for all these kids.

More than half the professional participants mentioned themes that reflected the level of acceptance of children with autism in the society, although they were almost equally split in terms of viewing society as accepting and supportive ($n=11$) or rejecting and critical ($n=12$).

Among professionals who viewed society as accepting and supportive, they primarily identified the traditional Indian *joint family system* as a positive factor about the culture. For example,

The help of the neighbors, [hard to hear], the neighbors pitch in if there is a need, the relatives pitch in. If you are sick, your aunt or someone will come to help. The social ties, the joint family system, the neighbors, extended families do help financially and physically. The physical and emotional support is more important.

Another professional noted,

Family system. When you have families, they support. You know it's a help. Because I don't know in the US if you have... you can't have a job and you know have a child because you know it's like your job expects you to be there 8 hours. No one is going to say, ok fine you have a child like this, I am going to send you off and then you can come back anytime you want. [Here] they're more open. We have joint family living, so grandparents can take care of the children when you have a job to run to. But in the social economic status who are a little lower than that, there are parents, grandparents who help, or neighbors, very helpful neighbors. Sisters here...like, take school for example. You know, one parent comes back late, the other is taking care, showering the child with love and food and everything. We are you know as a culture we are more united. We are not estranged. Tomorrow, or at midnight you have a problem, you just knock on your neighbor's door, he is going to rush with you to the hospital. That way yes we are open.

Yet another professional commenting about what it was like for parents to raise a child with autism in India observed,

Raising a child with autism... I don't particularly know about other foreign countries, but here, everyone will support the child in all the ways. Whatever they can help, they'll do that. Grandparents or siblings.... I have seen it.... They [siblings] always support the brothers or sisters in such a way that they will encourage them. . . . But, in foreign countries, there won't be much emotional support because they won't have family support. Here everyone will come and support... cousins, everyone.

Among professionals who believed that society and extended family can be critical (n=12), many of them mentioned the amount of stress and rejection that parents of children with autism faced from close family and neighbors as well as the larger community. One professional talking about the traditional role of a woman as a wife and daughter-in-law of the household made this observation.

Be it the in-laws, be it the parents, be it husband or whatever it is, all of them have to support because it [providing treatments or education for child] is expense. When most parents would come in here, they are neglecting so-called home and their duties. And, they say 'I am not fulfilling the duty of a daughter in-law, I am not fulfilling a wife's duty,' and maybe if they had a second child, [duty] as a mother...so many duties because 'I have to run around for this child'. And that is a decision made by. . . a lot of parents haven't given therapies because they [extended family members] feel 'ok fine if you are going to go give this therapy, that means you are not going to be here doing the other thing. So is it worthwhile? Are my comforts [i.e., other family members] looked into first before I [extended family members] say ok go ahead for the child?'

Other professionals spoke more generally about the society's reaction to children with autism, mainly caused by their ignorance of the condition.

Like you know, I mean it is considered still a social stigma you know. Taking a child out and I mean even here, if you stand in the autorickshaw stand, if you ask somebody for this place, and they'll say "that place where the crazy kids go, right?" I mean, people still raise this question, you know, I mean so that's one of the biggest difficulty we have.

Another professional noted the social stigma and resulting embarrassment that many parents often face when taking their children out in public.

... lot of stigma attached to this diagnosis. Social stigma big time. I have seen parents... however they understand the child, they fail to take them to social gatherings or somebody who comes to home, they fail to introduce the child to them. Because they see like it is a curse given by God or something like that. That still prevails in India that is for sure.

Or,

... in the Indian society... there are more elders who just start questioning, what is happening to your child? What have you done for this child all these days? So... it is very difficult for parents to answer the society.

See Table 17 for theme clusters about professionals' views about autism in the Indian culture, source statements and references for each, and exemplar statements.

Table 17.

Professional Report: Autism in India

Theme Name	n	f	Exemplar Statements
Problems with resources, expenses, and accessibility	20	62	<p><i>It is a big worry. Uhh... we have, as the school, looked in to something as a vocation for these children because... we are looking in to small prevocational areas now with our 13 to 15 year olds. But, I still feel they will need some sort of assistance. That is an area that... I think in the whole of India it is very very slow. Because only now we are working with the younger lot. And, now centers are opening up more and more for the younger children. But for the older community, we do not have too many... that is what we believe. So, we do not know.</i></p> <p><i>And the biggest lack out here is no coordination between therapists. No proper structure or documentation is there, so there is no proper reference, and in turn again it's all on the negative for the child and the parents.</i></p> <p><i>Yeah I like RDI very much. I have attended you know.... Even though we work with ABA and all these things, my aim is you know I mean whatever good everywhere, we should pick it up and use it, you know. There is no barrier in that. But, we don't have professionals here, and it is very expensive, and documentation wise it is very very difficult. If you teach them a behavior, you have to video-shoot and send to your teacher and she has to give you feedback, I mean it's like this actually, I mean the implementation process is very difficult.</i></p> <p><i>We have to work hard.. otherwise, I don't think really, you know as a special teacher, me, my director, full teamwork with parents support, government support... we have to set up something for these kids. Vocational training or something, you know, and we should be more clear.</i></p>
Need for more awareness, acceptance, and mainstreaming	16	35	<p><i>Society has not much idea about this, about autism. They need more awareness. I hope they will be able to be included in the society. When society understands about these children, they should be included.</i></p> <p><i>More awareness would bring about more acceptance level.</i></p> <p><i>In terms of school, what I would like to say is, there should be more awareness about mainstreaming. Because, you know we have really many children who can be mainstreamed, but you know, since...there is not enough awareness, I mean they are being seen differently kind of thing. Because mainstreaming is like a therapy for them. The younger age, I am</i></p>

Table 17 (continued)

			<p><i>not talking about the bigger children. 4, 3.5 etc. if we mainstream, there is a chance for many of their problems to get solved. Uniformity will come, reading from the society will come... children will learn those things only then. But, that opportunity, we are not able to provide for many children.</i></p>
Improvement in awareness, acceptance, and resources	14	31	<p><i>Earlier, you know, there was a lot of unacceptance. Earlier trend was more unacceptance. Now it is becoming gradually more accepted. Of course now that's why I said, in four years, the approach has been different. We are seeing people and parents opening up. It is uh they are open to talk about it these days than it was before, and there is more acceptability now than it was four years back. That is something I have seen.</i></p> <p><i>Acceptance also... I think most of them are like, ok early interventions are coming, you can see in school itself...you know. It used to be... ten year old boy and all without any intervention used to come and we used to we used to struggle, whereas now even 2.5 year old children have some intervention before coming. And you can see the difference also. So that way I think we have improved a lot.</i></p> <p><i>In India, now lots of people have awareness about autistic kids. Before I started my career in 2001, no one knew what autism was. They had a big... they didn't know the difference between MR and autism. Lots of people will think autism means poor brain growth and intellectual disability. But, now, it is quite good. Lots of people know what autism is, what OT is, what is speech therapy, what is the difference, why are these therapies important...like that there is more awareness now. In my work experience, I can see this difference. Now, if we can get more well-equipped, good centers and things like that, then it will be really helpful for autistic kids. That is what I feel.</i></p>
Society and extended family can be rejecting and unsupportive	12	27	<p><i>Criticism from society. Neglect, isolation from the society.</i></p> <p><i>Same family, you know, if you have a grandparent who is saying "don't do" means you know the mother can't do anything. Same thing with financial support also. The father is only making this much, he cannot pay for speech therapy, the mother cannot take the child.</i></p> <p><i>If it.. if this child is traveling in a bus, doing some behavior problems, and community other peoples are not accepting that, and they are scolding her. Because they [child] are looking normal, they are scolding her.</i></p>
Society is supportive, accepting, and nurturing	11	17	<p><i>Positives of the culture... one, we are very accepting of differences. (pause) I mean, increasingly you don't find people saying "paavam" (an expression of pity) or how sad or anything like that. They are even kind of matter-of-fact... you know, often I don't even see them turning and looking if someone is doing something very odd or giggling at them... nothing of that sort, I mean people just mind their own business as far as I can see. Or, they may be well meaning and they come and tell you, ' oh, he is not talking, apply honey on his tongue or go to this temple ' or whatever...</i></p> <p><i>The joint family system is a positive.</i></p> <p><i>Tribal communities... have family life.. kind of joint-family system. Where they're giving all kinds of support, they are not seeing the child's problem at all, if you ask me. They are seeing the child, ok that they are accepting the child. No way they are feeling the child is burden to the family, whereas in city life, the family is feeling more burden, more expensive, more time-taking like that. Whereas the other tribal community and rural</i></p>

Table 17 (continued)

community that kind of thinking is not there.

Note: n = number source statements that fit this theme; f = frequency of reference.

Discussion

Utilization of an exploratory, qualitative methodology served the purposes of this study well, as it provided a chance for parents and professionals in a southern Indian metropolitan city to describe in their own words their experience of raising and/or working with children on the autism spectrum. It also provided an opportunity for the investigators to: (a) explore beliefs and practices of Indian parents and professionals in one South Indian city regarding autism spectrum disorders, (b) gain a better understanding of the nature of parent-professional relationship and the level of collaboration between families and professionals around childhood developmental disabilities such as autism, and (c) gain a better understanding of ‘the state of things’ in this city with respect to autism spectrum disorders. In general, both the parents and the professionals in the study were eager, forthcoming, and gracious in their participation and generous with their time throughout the course of the interviewing process. This southern Indian city offered a rapidly growing set of resources to children with autism, including treatments that are practiced in the Western world and other treatments that are unique to the local heritage.

The following discussion section is organized by the main categories of the study’s findings and the thematic clusters under each category that emerged from participant interviews. Similar to previous sections, the discussion section is also presented within the Bronfenbrenner (1994) framework utilized in this study; organization progresses from categories relating to individual experience of parents and professionals and their beliefs and practices regarding autism spectrum disorders at the micro- and meso-systemic levels to themes related to their overall perceptions of autism spectrum disorders in the cultural context at the macro-systemic level.

Beliefs about Causes of Autism in South India. India is a nation that encompasses two distinct macrosystems: It is a modern country with cutting-edge scientific ideas and informational technologies, and at the same time it is a diverse nation with distinct cultural and religious traditions and beliefs dating back many thousands of years. Interviews with parents and professionals revealed that their very personal beliefs about the causes of autism drew from both of these worldviews. They were scientific (*genes, biology*), and in the next breath they accepted the *karma* that brought autism to their doorstep. Although some individuals clearly preferred one or the other version of reality, these seemingly distinct models co-existed comfortably and without contradiction for many in this group.

Daley (2004) observed that although there has been evidence in the literature to suggest that professionals and families maintained a variety of beliefs about causes (e.g., biological, environmental, psychological etc.), no single view of autism has emerged from within India. In the current study, the overarching theme across parent and professional interviews reflected that most participants *did not know*, or were *unsure* about what caused autism. This lack of certainty matches the perspective of most Western scientists and practitioners (Rogers, 1998; Volkmar et al., 2008), as other than evidence that something genetic is involved (Bailey et al., 1995; Rogers, 1998; Volkmar et al., 2008) there is no clear consensus on what is causing autism in one child and not another child. Other than this general view, however, findings from this study were consistent with what Daley reported in 2004. Although all parents and professionals offered many explanations for what might cause autism spectrum disorders, such as genetics, environmental pollutants, religious and spiritual reasons etc., it was not possible to identify one clear single view about specific causes among participants.

Both parents and professionals in the study mentioned some universally held beliefs about causes of autism (e.g., genetics) although only a minority mentioned more controversial Western beliefs such as vaccines and specific environmental toxins (see Volkmar et al., 2008). Consistent with existing literature, a significant number of participants, especially parents, also mentioned themes that are culturally unique, especially spiritual and religious beliefs in *karma*, sins from the past life, destiny or fate, and God's will (Dalal & Pandey, 1999; Gupta & Singhal, 2004; Kaul et al., 2003). Contrary to what is suggested in current literature, however, these spiritual beliefs served in a positive way as a means for families to understand and cope with their child's disability rather than influencing their decisions about whether or not to seek treatment. As one mother said, *see, as per the religious beliefs that I have been brought up, I tend to believe that all what is happening is a reflection of what has happened in the past, that I believe. So, I believe that there is something I can do to change it, I will definitely do.* Thus, for many parents in this group, their beliefs in the Indian concept of *karma* served to both provide an understanding of the past and better clarity about the steps that they need to take in the future. Professionals also made this observation about the interesting duality in families' beliefs about causes of autism. As one professional noted, *there are people who think of it both ways. At one level they think it's their karma, but at another level they accept the scientific part of it. They are willing to accept... but they want to fight...they just don't want to stay with the thought that this has happened, this is karma, so I will not go further.*

In other words, while some parents reflected a fatalistic approach in their understanding about what *caused* autism, they did not reflect a fatalistic approach in terms of whether to seek treatments and interventions for their child. Of course, the families we interviewed were all on site at schools where their children were being served, and so they obviously "believe" in

seeking schooling and treatment for their children with autism. We cannot know whether (or how many) Indian families exist who do not seek treatment for their child who is developing in a different way. As there are fewer services for children with disabilities in the villages and rural areas in India, there are doubtless children who lack treatments and schooling. There is no way to know, however, whether their parents wish they could get a diagnosis and access to special treatments or whether they simply accept that their child seems to be different but there is nothing to be done. Nor is there a way to know, beyond the families who were interviewed here, how common is a belief that it is their child's *karma* to live a life with these special needs and the parents' *dharma* to simply accept it.

Consistent with Daley's (2004) observation about autism in India, about a quarter of the professionals in the sample mentioned themes that are seen as outdated and rejected in most parts of the world. These included mother-blaming beliefs in "cold parenting" and social isolation due to two-parent working homes as being causes of autism (Dyches, et al., 2004). This theme reflects both misinformation among some professionals about autism spectrum disorders and the impact of these beliefs on the professionals' interactions with the families that they worked with. These professionals were both implicitly and explicitly critical of families for abandoning the time-tested household of the Indian joint family system and going instead to nuclear families. Even if they did not name "cold parenting" directly, some blamed TV and the media as replacing the *warm touch of parental care*. Notably, professionals who explicitly believed that autism was caused by cold parenting and attributed parental blame for the child's condition or that it occurred due to a combination of organic factors and lack of parental attention were also, in general, negative in their overall assessment of families. These professionals viewed parents as

being uninformed and uneducated, and described their work with families as *highly challenging* and *emotionally draining*.

Finally, parents and professionals spoke about their beliefs from different conceptual frameworks and reflected different experiences of the same disorder. For parents, the question of “what do you think caused your child’s autism” was personal, and their experience of autism spectrum disorder was in the microsystem level and thus quite proximal (Bronfenbrenner, 1994). Their responses reflected what they believed caused autism in their own son or daughter specifically (e.g., *I was depressed during my pregnancy*), and few parents made any comments during the course of the interview that reflected beliefs about causes of autism spectrum disorders in general, even when prompted. For professionals, however, this question was more academic in nature, and their experience of the phenomenon of autism spectrum disorder was more distal. Thus, their responses reflected a more scientific and academic viewpoint about the condition (e.g., *research shows it is genetic mainly*), and most of them referenced the notions that are familiar and endorsed by the scientific community.

It is important to consider this difference in conceptual frameworks about autism between parents and professionals (i.e., personal versus academic), because parents and professionals have differing interpretations of what a child’s disability means (Singh, 1995). Parents and professionals both attach different meanings to beliefs about causes, symptoms, and treatments. For example, while “genetics” as a cause for autism is a neutral scientific fact for professionals, for parents, it might mean something more personal and guilt-provoking. They did not want the genetic problem to be in “their side of the family,” and they feared the judgment of their in-laws. Many mothers shared that their in-laws were critical for having *a child like this*. One very worried-looking mother noted *I don’t know* [what caused child’s autism]. *I married a relative*.

Wherever we go, all the doctors say that this was the reason. That I married within the family.

So, genetics is less a scientific reason than a personal failure for some of these parents, and it is of no comfort to them to tell them that it was “just the genes” that caused their child’s problems. It is important for professionals to understand why parents might be devastated and shamed by the news that genes play a causal role in autism spectrum disorders, since understanding this difference would be especially useful to increasing professionals’ insight about “where parents come from” and consequently, their view of and interactions with the families.

Treatments and Services. Similar to beliefs about causes, treatments and services that were utilized with children identified with an ASD among this group of participants also appeared to be influenced by the two distinctive macrolevel cultural beliefs in India (i.e., scientific and evidence-based, vs. traditional and spiritual). Thus, consistent with existing Western literature (Goin-Kochel et al., 2006), children with autism referred to in this study received a combination of treatments and services in a school, community, or home-based setting. Parents and professionals both described school-based services that were to a large extent informed by many Western approaches to intervention in the areas of special education, speech and language therapy, occupational therapy, and participation in groups and activities. In addition, most parents also implemented special routines and diets with their children outside of the school setting such as taking them to the beach for them to feel the sand on their feet, or avoiding certain foods to control allergies or weight-related issues.

In a pilot online study conducted by the investigators with Indian families settled abroad, about half the parents reported that they would prefer to use a combination of Western and Indian approaches to treatments, if these unique traditional Indian treatments were made available to them in their host countries (Ravindran & Myers, in press). This indeed seemed true

for the current sample of parents living in India who, in addition to using treatment approaches informed by a Western perspective, were keeping with the traditional Indian beliefs and practices (Daley, 2002). Thus, more than a third of the parents in this study followed spiritual routines and offered special prayers for their child's recovery or betterment, and more than half the parents used traditional Indian treatments such as Ayurveda, Siddha, and Yoga.

Several professionals, too, acknowledged that their treatments were currently from the West, but that they wanted their nation to develop more practices and healing techniques rooted in the Indian culture. Professionals noted the importance of developing *indigenous programs* for children with autism in the country, and lamented the practice of implementing Western-based treatments (e.g., TEACCH, RDI etc.) with little to no guidance or training and while often lacking the infrastructure needed to implement such treatments with fidelity. These professionals stressed the need for developing more culturally-appropriate and culturally-effective treatment programs, based on the country's long and rich history and unique systems of healing and medicine. About half the professionals reported that they already used traditional Indian practices in their school or practice. Yoga and Ayurveda were frequently mentioned by professionals as being helpful, and one school that we interviewed at was dedicated to the Indian system of Siddha Medicine and natural healing. In general, both parents and professionals were influenced by the broader cultural context in terms of selecting what treatments to use with the children and saw value in using a multi-pronged and combined approach to treatments and interventions. As one professional summed up, *whatever works* appeared to be the overarching theme in selection of treatments and services by parents and professionals.

Expectations from Treatments. Parents' expectations for their child's future reflected common social and cultural values that are prized in the broader Indian culture in the child's

macrosystem (Bronfenbrenner, 1994), as well as more proximal processes such as parents' beliefs about causes and their perception of their child's disability (Mandell & Novak, 2005). For example, 18 out of 19 parents in the study mentioned that they were mostly *unsure* or *did not know* what caused autism, in addition to venturing guesses about other factors such as genetics, issues related to pregnancy, and environmental factors. Parents also reported a range of severity from *very mild* to *quite severe*, but it was not possible to know how accurate they were in their assessment, since we did not observe the children except as they walked across the terrace or hallway. For example, one mother who described her 9-year old son's autism as *mild only*, reported that he had little to no expressive communication, but was *very bright* and would *repeat everything we teach him accurately*, and *seems to remember everything after only one time of seeing it*. This mother also reported that her son was *50-50* in adaptive skills such as personal hygiene, but in reality he needed constant monitoring. Mandell & Novak (2005) observed that parents' beliefs about causes have a significant impact on their perception and understanding of their child's disability and the parent's expectations for their child's future: if families believed that their child's autism was a lifelong disability, whose symptoms and related disability may be alleviated to some degree but not eliminated completely, they are more likely to make stable treatment choices and have more modest expectations from those treatments. Given that parents in this study mostly expressed confusion and a lack of knowledge about what caused their child's disability, their impressions of how severe or mild their child's autism was also varied considerably and were somewhat confusing to understand. Their expectations from treatments ranged broadly from *he should at least not be running around so much* to *I believe she will be completely normal in 10 years*.

Over 50% of the parents hoped that their children would be cured of their autism or that

treatments would help them become *normal*. A majority of parents also spoke about their desire for the child to be *accepted in the society*. While parental hopes related to social mainstreaming and cure of their disabled child are often universal and seen in most parents of children with disabilities (see Christon et al., 2010; Mandell & Novak, 2005), the notion of societal approval and acceptance has a particular significance in the collectivistic Indian society. Children growing up in India often hear their parents and grandparents talk passionately about the family's "standing in the society" and of upholding one's "family name," and this cultural need for social approval and acceptance often serves as the primary driver for achieving individual success. In fact, in various Indian languages, children in India grow up hearing maxims about the importance of being successful "so that the family name can be honored and upheld." This is in contrast to most individualistic cultures where the primary driver is individual success, for the sake of that individual, without mention of the effect on the extended family; social approval and acceptance come lower in importance. Thus, in this study, parents' expectations for their children were shaped not just by the individual needs of the child and family in more proximal levels, but also by the larger macrosystemic cultural values and beliefs concerning the family (Bronfenbrenner, 1994; Skinner & Weisner, 2007).

Parent-Professional Relationships. One of the major aims of this study focused on understanding the 'essence' of the parent-professional partnership in the Indian culture within the context of developmental disabilities, since existing literature on the topic in India relates to the doctor-patient relationship within a medical model (Kaba & Sooriakumaran, 2007). We sought to understand the essence of this relationship based on the responses that parents and professionals provided during the interview to direct, straight-forward questions (e.g., "what is it like working with [parents or professionals]?", "how do you resolve disagreements that arise?", "what is your

role in selecting and implementing treatments?’’), as well as from our own interpretations of statements that participants made throughout the course of their interview. We kept summary notes on each individual participant about their general outlook and approach toward the other group as well as field notes on what we saw and experienced at each site (see Table 4). From all these sources, we developed overall impressions of how parents and professionals viewed each other and got along together, in the context of helping the children with autism.

Similar to other themes related to beliefs and practices about autism, the parent-professional relationship, too, was greatly informed and shaped by broader macrolevel factors in the Indian culture that trickled down to more proximal mesosystem processes such as parents’ and professionals’ relationship with one another (Bronfenbrenner, 1994). For example, parents and professionals were both modernistic in their thinking in that they were attempting to move toward a more collaborative and partnership-based approach to treatments as seen in the West (Dempsey & Keen, 2008; Kaba & Sooriakumaran, 2007). At the same time, both the parents and the professionals seemed to retain and accept—with no resentment—the centuries-old view of health care and teaching as being among the most noble and worthy of professions, which accords a higher level of social status and respect for these professionals (Kaba & Sooriakumaran, 2007).

In general, parents in this study overwhelmingly reported themes of grateful satisfaction and positive regard for the professionals that they worked with, especially in their child’s current school-settings, and satisfaction with treatments and services that their child was receiving. Parents were grateful for the kindness and compassion shown by their child’s teachers and therapists toward their child and themselves, and repeatedly stated that they [professionals] *listen to all our concerns very well.*

Dempsey & Keen (2008) noted that the ways in which professionals support children with disabilities and their families has the potential to enhance or hamper child and family outcomes. In that respect, the parents' high level of satisfaction and sense of collaboration that they perceived from the professionals in the child's mesosystem (Bronfenbrenner, 1994) are reflective of the increased likelihood of positive outcomes for the child in the microsystem. Only a minority of parents had anything negative to say about professionals, and even then they referred to physicians that they had consulted with in the past about their child's disability, rather than the related health professionals and therapists that worked with their child currently in the schools. Among the various factors that contributed to parents' overall sense of positive regard and satisfaction, an important factor was the parents' sense that their relationship with the professionals was indeed collaborative and mutually respectful. Many parents mentioned the high level of home school communication adopted by their child's school and explicitly stated that they felt heard. Indeed, we were impressed by the extent of home school communication that occurred in this group of participants, and the high level of consistency between parent and professional reports of the lines of communication being open and frequent. A majority of parents also believed that selection and implementation of treatments was a collaborative process and that they made decisions based on input from close family, friends, as well as the professionals.

Less than half the parents believed that professionals had the ultimate say in decision-making about or implementing treatments; however, these parents, too, were positive and happy about this situation. As one parent expressed, *once we decided which school to put her in, all other decisions are taken by her school*. Parents were fully comfortable acknowledging *I expect the professionals to know more than I do* and conveyed a sense of implicit trust that the

professionals would do the best for their child. These parents emphasized the extensive training that professionals have in the field, and respected their opinions because the professionals saw *all types of kids*. Many of these mothers believed that playing a more active role in the child's treatments would be an *interference*, and that it would not be *good for the child*.

Indeed, contrary to what is often suggested in early intervention literature (Carpenter, 2000; Case, 2000; Dempsey & Keen, 2008, 2009; Kalyanpur & Harry, 1997; Singh, 1995), parents in this study were mostly happy and comfortable with their interactions with the professionals even when acknowledging that the relationship was more vertical in nature. These parents did not consider themselves an "equal partner" in the parent-professional relationship, and more importantly, did not have an expectation to be so. An important reason for this could be that the health and teaching professions are still considered noble and highly worthy professions in India (Kaba & Sooriakumaran, 2007). Doctors, and for these parents, the therapists working with their children, are still afforded a certain status and standing in the society, thus parent-professional relationship is more clearly hierarchical in nature, with professionals being accorded more 'power.' It could also reflect the fact that medical litigation rates in India are significantly lower compared to Western countries (Kaba & Sooriakumaran, 2007), and so parents typically adopt an "avoid rather than confront" approach when disagreements arise. Indeed, the few parents who acknowledged having disagreements with professionals that they could not resolve through dialogue stated that they simply *left* to go somewhere else, sometimes even leaving their homes to move to a different city.

Professional responses, on the other hand, reflected more diverse views about families in general and their assessment of the parent-professional relationship. In contrast with parents who nearly all thought their relationship was positive, collaborative, and trusting, professionals

mentioned a mixture of themes that ranged from positive and collaborative to negative and challenging. A majority of the professionals described their relationship with parents as being professionally-driven, even while acknowledging collaboration and positive regard for the parents, mirroring the themes reflected by parents in the study about broader macrolevel values in the culture, and what is seen in the existing literature (Bronfenbrenner, 1994; Kaba & Sooriakumaran, 2007).

It is important to note that professionals who spoke more positively about the parent-professional relationship also had an overall positive view of the families and were empathetic to their struggles and concerns. These professionals made more deliberate efforts to be collaborative and family-focused while planning interventions for the child, while also acknowledging that professionals knew more and were more educated than parents in the area of autism. Professionals agreed that *families are the most important* and *if I had a whole family to support me, my job would become very very easy*.

On the other hand, professionals whose description of the parent-professional relationship fell into themes that were negative and explicitly critical, also tended to have more overall negative views about the families, were more authoritarian in their approach, and viewed parents as being uninformed and uneducated. Professionals' description of the families that they worked with often sounded harsh and critical, and they commented on the parents being *highly challenging* and having *their own* [mental health] *issues*. Notably, one of the most interesting findings from this study revealed that one factor that appeared to closely influence how a professional viewed and worked with a family depended at least in part on what they believed were causes of autism. In this study, professionals who explicitly stated beliefs about autism being caused by parent-related factors such as "cold parenting" or lack of emotional input from

the parents mostly had overall negative views of the family; only one professional with this belief about cause had a positive view and collaborative mindset. The remaining 85% of the professionals who attributed blame to the parents were all more authoritarian in approach and had a “professionals know best” outlook.

This finding about how professionals’ beliefs about causes of the disability influences their views of and work with the families is particularly noteworthy when viewed in comparison to the other group: out of the 14 professionals who held more scientific-based views (organic causes such as genetics, biological, environmental toxins, or a combination of two or more of these organic causes) or stated that they *did not know* what caused autism, only 1 had a negative view, while 13 had either positive or ambivalent views.

Bernier et al. (2010), Mandell & Novak (2005), and Singh (1995) observed that parents’ perception of their child’s disability is to a large extent shaped by their cultural views and norms. The current findings show that it is equally true that professionals’ worldview and broader cultural beliefs informed their concepts of disability and vice versa. The “cold parenting” hypothesis, first introduced in 1943 by Kanner and spread by Bettelheim in 1967, is now soundly disputed and rejected by nearly everyone in the West (Dyches et al, 2004; Ravindran & Myers, 2011). The cold parenting model takes on an almost macrosystem-like world view, which stands in contrast with a scientific world view. Under the macrosystemic belief of seeing parents (and especially mothers) as “bad parents” and the source of the child’s autism, these professionals seem to have let this view spread into a generally negative opinion of these parents. Accordingly, in their working relationship with the parents, there was no desire to be collaborative in making decisions or implementing services. Instead, they maintained a professional distance that was authoritarian, negative, and non-collaborative. In contrast, the “scientific macrosystem”

professionals were more positive and collaborative in their mesosystem relationships with the parents. This is an important finding that highlights the need for professionals to not only be more aware and accurately informed about a disability and its causes, but also to be thoughtful about their perceptions and biases. Being thoughtful and deliberate in their efforts to reflect on some of these core internal processes and issues would then help them to pause and reflect on their views and decisions about treatments and approach with families, thereby increasing the likelihood of better outcomes for the child.

Autism in India. In addition to providing us with the opportunity to explore proximally what it was like for parents and professionals to raise and work with a child on the autism spectrum at micro- and mesosystemic levels (Bronfenbrenner, 1994), the study provided us with an understanding of broader macrosystem influences that shape the everyday experiences of the families and professionals that participated in the study. The broader overarching theme about the participants' perception of the 'state of things' regarding autism in India reflected the same kind of duality in thinking and experience that parents and professionals endorsed throughout the course of the study. While on the one hand they acknowledged increasing awareness and acceptance as well as the increased availability in resources, on the other hand, parents and professionals uniformly talked about problems with access and expense and the need for more awareness and acceptance in the society.

All parents and professionals acknowledged that awareness and understanding of autism spectrum disorders in India was growing every day. Even within the last five years, there has been a dramatic increase in resources for autism including the availability of different special schools dedicated to serving these children, professionals seeking specialized training in the field, and a wider variety of treatment approaches and options for children and their families.

Parents and professionals identified a number of strengths that the Indian culture offered with regard to caring for a child with autism, the most important and significant of which was the level of social and emotional support that they received from close friends and extended families. The positive changes in India with regard to an increase in awareness and acceptance of autism as a serious childhood disability is reflective of the child's broad chronosystem or "time in history" (Bronfenbrenner, 1994). In the wake of India's increasing modernization, technological advances, economic boom, and wider global visibility, there is an increased capacity for parents and professionals to access information that they seek and make their voices heard. The chronosystem change has set in motion changes at a macrosystem level, where the culture as a whole is becoming more aware, inclusive, and accepting of children with disabilities. These changing macrolevel cultural factors are no doubt reflected in parents' and professionals' personal views about diagnosis and intervention as well as the parent-professional partnership. More families and professionals are seeking a collaborative approach to service delivery at a mesosystem level, even while acknowledging more traditional cultural values and a high level of comfort in professionally-directed relationships.

However, parents and professionals also almost uniformly addressed difficulties that still significantly impacted their everyday lives and outcomes for children on the autism spectrum. For example, a majority of parents saw the society as being critical and rejecting, felt stigmatized, and noted the need for more acceptance of the child in the broader culture. Many parents talked about the problems with resources, expenses, and accessibility and voiced a need for more services for children with autism spectrum disorders. Parents and professionals were both worried that autism intervention in India currently targeted only the younger children, and that there were very limited options for what services may be available to their children when

they become adults. Professionals expressed a need for more training in the field and access to higher quality of resources, while parents wished that the government did more to help their families. We had the fortune to speak with families whose children were already identified with an ASD and were receiving services. However, we can only assume that there are many more children who are underdiagnosed, misdiagnosed, or simply missed in the bigger picture. Given the vast diversity in culture and economic standing of families, geographical spread of towns, villages, and cities in each state, and the rapidly increasing population, the task of providing diagnostic and intervention services for all children who have an autism spectrum disorder in India is an almost impossible task at the current time. However, the study's participants provided us with valuable information about where some of those gaps exist and how we can begin to think about addressing those gaps in incremental, systematic steps in the future.

Limitations

Given the paucity in exiting literature in this area, especially with regard to South India, the study no doubt makes a valuable and significant contribution. However, it is important to address some of the study's limitations. First, although we had a reasonable sample size for a qualitative study of this nature, it was still relatively small when we consider the "bigger picture" --- there are about 2 million children with autism across India, and 94% of them do not receive any services (National Sample Survey Organization, 2003). Of the 6% that do receive services, we spoke with 19 families. Second, all participants were drawn exclusively from special school settings in one South Indian city, which make findings less generalizable across other cities and villages in different parts of the country. Third, given the extent of diversity within the Indian culture and within Indian families, findings from this study may not necessarily represent the typical experience for all South Indian families or for families in other parts of India. The fact

that these children were enrolled in these special schools in itself makes them different from the vast numbers of other children who have not been diagnosed yet or do not receive the appropriate services. We do not have a good answer in terms of how to bridge that gap, but we recognize the limitations that it presents to the scope and generalizability of findings. Fourth, in terms of demographics of the participants interviewed, although not a deliberate plan of the research design, it is notable that we only had the opportunity to interview mothers. This is fairly typical of the broader social and cultural setting in India where mothers play a more hands-on role with regard to childcare. Nevertheless, the findings from this study only reflect the experiences of one parent in these primarily two-parent households, thus limiting its scope. It would have, no doubt, been valuable to get the fathers' perspectives on raising a child with autism and gain better understanding of their concerns and comments. It is also important to acknowledge that almost all the participants in the study were Hindu. Although this is also expected, given the overall representation of various religious groups in the broader population, it is difficult to predict if some of the culturally-based themes were reflective more of the tenets of Hinduism or broader Indian cultural values. It is also not possible to say how similar or different the interviews might have been with a larger number of Muslim or Christian participants or those from the many other faith groups in India. Finally, even though we were thoughtful in our approach to preparing for and conducting the interviews and took necessary steps to eliminate responder bias, it is likely that participants' experience of the interviews and their response to questions were influenced by who they were sharing their experiences with. Apart from the racial and cultural differences between the two interviewers, it is likely that language barriers, too, may have had some impact on the depth of information that participants were willing to share. For example, unlike the native speaking investigator, the second

investigator could not explain or clarify a difficult question in the participant's native language. Although the richness of data gathered from each interview was fairly consistent in terms of the quality and content of themes that emerged, we recognize the potential for why the differences between the interviewers may have raised some issues for some participants.

Conclusions and Future Directions

Findings from this study provided us with a "first pass" look at what the experiences are for families and professionals in one southern Indian city raising and working with a child with autism. It also provided us with a sense of the how parents' and professionals' cultural beliefs and values affected the course of treatment selection and implementation, and the parent-professional relationship.

Culture frames our worldviews and helps us to make sense of what we know. Cultural beliefs and practices are dynamic and constantly evolving which leads to a significant amount of variability between and within cultures. One of the pivotal themes that emerged from this study was that, despite being members of the same broad cultural group and sharing many of the same traditions and practices, parents and professionals have different worldviews about a child's disability. These worldviews influenced how they perceived and understood a child's disability, and shaped their beliefs and practices in terms of providing appropriate care for the child. Specifically, for parents in this study, their child's autism was an intensely personal and proximal experience that affected their lives and their families every single day. For most professionals, regardless of their level of compassion for these families or their passion to serve, autism was a more distal, academic and clinical experience that they wanted to leave at the door at the end of a long work day. This conceptual framework is an important one to consider, since understanding these inherent differences in one's framework is an essential first-step in understanding how to

establish a mutually respectful, trusting, and collaborative relationship, especially when managing a child's disability.

From an ecological standpoint (Bronfenbrenner, 1994), within the broader macrosystem, in terms of the Indian culture, the study highlighted the existence of the two seemingly contradictory yet perfectly compatible cultural beliefs (i.e., traditionalism and modernism) that influenced individuals in the microsystem on an everyday basis and the relationship between elements of one's mesosystem. With regard to ASDs, both groups of participants comfortably acknowledged beliefs and practices that were both modern (scientifically informed beliefs and treatment choices) and traditionally unique to the Indian culture (spiritual Indian beliefs and traditional Indian medicines). Similarly, parents and professionals also endorsed seemingly opposing yet completely compatible views about the nature of their relationship with each other (directive *yet* collaborative).

The study highlighted that, similar to most parents around the world, parents in the Indian culture want to feel included in the treatment process and desire a relationship defined by mutual trust, respect, and honesty. Family-focused models in a Western perspective aim to acknowledge the context of the child, take into consideration the strengths and limitations of the child and the family, and introduce appropriate, sustainable, and sensitive interventions (Carpenter, 2000). There is emphasis on parent empowerment and an ultimate goal to establish an "equal partnership" approach to managing a child's disability. However, unlike most Western cultures, an "equal partner" approach to family centered care may not be the most culturally relevant model for cultures around the world. Indeed, in terms of the parent-professional relationship, the 'essence' of the themes that emerged from the data indicated that, for parents in this study, it did not matter to them if the professionals were being directive and authoritarian; it "fit" in their

cultural framework and fulfilled the parents' 'expectations' for the professionals to assume a more directive 'expert' role. What mattered to these parents and formed the crux of their definition of a collaborative relationship were the elements of respect, trust, honesty, and most importantly, the belief that they were "being heard."

Dempsey & Keen (2008) observed that the ways in which professionals support children with disabilities and their families has the potential to enhance or hamper child and family outcomes. A notable highlight of this study was the finding that a professional's own beliefs about causes played a key role in how they perceived the families that they worked with and the approach they adopted during their interactions with parents. This finding is consistent with Singh's observation in his 1995 review paper, and highlights the need for (a) professionals to not only be thoughtful about what a child's disability means to a family, but also be aware of what it means to them personally in terms of beliefs and their values associated with those beliefs, and (b) how this personal framework impacts their work with the children and their attitudes toward the families. After all, it is as important for professionals to ensure that a child with a disability receives the best course of care with the most empirically sound treatments, as it is for them to be sensitive and respectful of parents' needs and desires for their child (Ravindran & Myers, 2011). Adopting a more thoughtful and personally reflective stance in their approach to diagnosis, intervention planning and implementation would not only help professionals gain insight into their own perceptions and biases, it would also make their efforts to work toward mutually agreeable treatments (that may involve a combination of cultural practices) more fruitful.

The current study's utilization of qualitative methodology to gather data that were rich in detail and embedded within the surrounding context helped to increase our understanding of the Indian parent and professional perspectives on autism in one southern Indian city. Replication of

similar studies in other parts of the country would be valuable in helping us to gain a more complete understanding of autism in the Indian cultural context. Qualitative research is also well-suited for development of theory that is grounded in the experiences of participants (Creswell, 2007; Morse & Field, 1995; Patton, 2002), and future studies would benefit from looking more closely at how some of the independent themes that emerged from the data in this study are connected and how they influence and impact one another. For example, how does a professional's belief about causes of autism influence the treatments that they select to deliver with children on the autism spectrum, as well as their expectations for the child's future? Thus, data from this study can be explored in more depth to understand other new relationships that may arise between the different themes and help us answer new questions. This would serve to generate more culturally appropriate conceptual paradigms about autism spectrum disorders, which would then lead to better understanding and culturally relevant practices.

Despite its limited scope and generalizability, findings from this study can be utilized to raise awareness and understanding about autism spectrum disorders in India among parents, professionals, and the larger society, and call to attention the need for more services and resources in local communities. The study also offers valuable information about the nature of parent-professional relationships with regard to autism spectrum disorders, and this knowledge may help us to improve parent-professional communication in clinical practice, (Dempsey & Keen, 2008; Ravindran & Myers, 2011; Skinner & Weisner, 2007), develop and implement interventions that are sensitive to the needs of the child and their family, and consequently, to an improvement in treatment outcomes for children with disabilities (Dunst & Dempsey, 2007).

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Appendix A

Personal Interview – Parent Version

Parent and Professional Perspectives about Autism Spectrum Disorders in South India: Beliefs, Practices, and Parent-Professional Relationships

Interview Questions and Prompts

1. Please tell me about your child:

- *Child Demographics:*
 - i. Age:
 - ii. Gender:
 - iii. Primary Diagnosis (Autism, PDD-NOS, AS, Other):
 - iv. Additional Diagnosis: (Seizure disorder, Cerebral Palsy, MR, ADHD, Other):
 - v. Age of child at diagnosis:
 - vi. Who made the diagnosis:
 - vii. Severity:
 - viii. If your child attends school, what kind of school does he/she attend?
- *Also a brief description of child:*
- *Brief description of family (if provided here; if not, ask in the end):*

2. What did you think caused your child's autism spectrum disorder?

- *Prompt 1: What did the professional (s) who diagnosed your child tell you about autism? What advice or information did they give you?*
- *Prompt 2: What do you think about it now? What do you think about autism spectrum disorder in general?*
- *Prompt 3: What did your family think caused your child's autism spectrum disorder?*

3. What do you do to help your child with autism?

- *Prompt 1: What services and treatments is your child receiving? (use this prompt if parents do not provide this information spontaneously)*
- *Prompt 2: In addition to treatments you just mentioned, what routines and practices do you usually follow at home for your child to help with his/her autism?*
- *Prompt 3: Do you have any spiritual or religious practices regarding your child's autism? Any special practices for health or diet?*

4. What services or treatments is your child receiving?

- *Prompt 1: Who bears the cost for these services? (If parent lists multiple people who bear the cost ask who is the primary group/person that bears the cost)*
- *Prompt 2: Do you receive any support from the government for these services?*

5. Are there treatments or services that you want to use, but cannot use or access?

- *Prompt 1: What are those treatments/services?*
- *Prompt 2: What makes it hard to use those services?*

6. **How are decisions made about what treatments to use for your child?**
 - *Prompt 1: What is your role in selecting treatments for your child with autism?*
 - *Prompt 2: What is the professionals' role?*
 - *Prompt 3: Does your family play any role in this process?*
7. **Once a decision is made about what treatments to use, what happens next? How do you go about getting your child treated?**
 - *Prompt 1: Is it the professionals at school or clinic who do the therapy, or do they also give you things to practice at home with the child?*
8. **What is it like working with the doctors and therapists?**
 - *Prompt 1: What happens if you disagree with each other?*
 - *Prompt 2: Do you wish it were different in any way?*
9. **Are you happy with the treatments and services your child receives and the professionals providing them? How much improvement do you expect to see in your child as he/she grows older?**
10. **What kinds of support do you get from your extended family in caring for your child with autism?**
11. **How has the community reacted to your child and family? Have they been accepting and welcoming? What difficulties have you had?**
12. **What do you think could be done to improve life in this community for people with disabilities?**
13. **How has having a child with autism affected your life and your family's life?**
14. **Where do you get support to manage everything?**
15. **What worries you most about your child with autism?**
16. **What are you most thankful for with regard to your child with autism?**
17. **Before we wrap up, can you tell me about yourself and your family?**
 - Relationship to child:
 - Age:
 - Marital Status:
 - Spouse's age (if married):
 - Religion:
 - Number of children (including child with disability):
 - Living arrangements (who all live in your household?):
 - Education level (highest degree attained):
 - Spouse's education level (if married):
 - Occupation:
 - Spouse's occupation (if married):
 - Total family income (clarify if yearly or monthly):

Appendix B

Personal Interview – Professional Version

Parent and Professional Perspectives about Autism Spectrum Disorders in South India: Beliefs, Practices, and Parent-Professional Relationships

Interview Questions and Prompts

- 1. What do you think causes autism spectrum disorders?**
 - a. *Prompt 1: What do the families that you work with usually think cause autism?*

- 11. What kinds of treatments do you usually use with children on the autism spectrum? What are the goals of treatment?**
 - a. *Prompt 1: Do you use any traditional Indian medicines or practices in your treatment? (e.g., Ayurveda, Homeopathy, Siddha etc.?) What are the goals of these traditional treatments?*

- 12. In your experience, does treatment differ depending on SES, religion, and other factors? What are those?**

- 13. Are there treatments or services that you want to use with your clients with autism, but cannot use or access?**
 - *Prompt 1: What are those treatments/services?*

 - *Prompt 2: What makes it hard to use those services?*

- 14. Who bears the cost for all the services that a child receives at your school? (If we know that services in the center are all provided by the govt., and families pay nothing, ask what they believe is true for other schools in the city. Otherwise, proceed to the following prompts)**
 - *Prompt 1: Is it primarily the family's responsibility?*

 - *Prompt 2: Do they receive any support from the government?*

- 15. How are decisions made about what treatments to use for a child with autism?**
 - *Prompt 1: What is your role in selecting treatments for the children that you see on the autism spectrum?*

 - *Prompt 2: What is the families' role in selecting treatments for their child with autism?*

- 16. Once a decision is made about what treatments to use, what happens next? How do you go about getting the child treated?**
 - *Prompt 1: Is it you (the professionals at school or clinic) who does the therapy? How much are families involved in their child's treatment? Do you also give you things for parents to practice at home with the child?*

- 17. Do you deliver treatment outside of the center, at the home of the child?**

- 18. What is it like working with the families?**
 - *Prompt 1: What happens if you disagree with each other?*

 - *Prompt 2: Do you wish it were different in any way?*

- 19. What is your (medical community) view of ASD? What do you think is the community's view towards persons with ASD?**

- 20. What does the future hold for many of these children?**

Vita

Neeraja Ravindran was born on April 6, 1980, in Chennai, in the southern Indian state of Tamil Nadu. She graduated from D.A.V. Matriculation Higher Secondary School, Chennai in 1997. She received her Bachelor of Arts in Psychology from Women's Christian College, Chennai in 2000, and received a Master of Arts in Psychology from SNDT Women's University in Mumbai, Maharashtra, India in 2002. Between 2002 and 2004, Neeraja worked with children on the autism spectrum in a school for children with various developmental disabilities in Bangalore, Karnataka, India. She worked as a Master's level Clinician in a private medical hospital in Pondicherry, India from 2004 to 2005. Neeraja began her graduate training in Clinical and Developmental Psychology at Virginia Commonwealth University in Richmond, Virginia in 2005, and earned a Master of Science in May 2008. She is currently a doctoral candidate in the Clinical Psychology program, with a dual focus in Developmental Psychology through the Developmental-Clinical Scholars Program at Virginia Commonwealth University. Neeraja will complete her pre-doctoral clinical internship training during the 2011-2012 academic year at the University of North Carolina School of Medicine at Chapel Hill as the child clinical psychology intern at the Carolina Institute for Developmental Disabilities. After completion of the clinical internship, Neeraja plans to pursue a one year post-doctoral Fellowship at the Carolina Institute for Developmental Disabilities, University of North Carolina School of Medicine at Chapel Hill.